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Palliative Care in California: Innovations in Hospital-Based Programs

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Palliative Care in California: Innovations in Hospital-Based Programs

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Palliative Care Program

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About the Foundation

The **California HealthCare Foundation**, based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. Formed in 1996, our goal is to ensure that all Californians have access to affordable, quality health care. For more information about CHCF, visit us online at www.chcf.org.

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I. Introduction

THE CALIFORNIA HEALTHCARE FOUNDATION HAS commissioned *The State of Palliative Care in California Hospitals* to alert, educate, and advise health care administrators, and in particular hospital executives and their boards of trustees, about the fundamentals of palliative care and the operational requirements for launching a hospital-based palliative care service. The project is intended as an important step toward increasing the number of hospital-based palliative care services and thereby improving the overall quality of care for seriously ill Californians. The authors, members of the Palliative Care Program at the University of California, San Francisco and nationally recognized leaders in palliative care training and education, have created a series of reports, each dedicated to a different aspect of the substance and structure of palliative care services.

This report provides an overview of innovative palliative care services and programs, both in California and nationally. The report also highlights curricular offerings at California's medical schools and reviews training programs available to other clinicians. There are two other reports in this series. *Palliative Care in California: Fundamentals of Hospital-Based Programs* introduces the concept of palliative care and discusses challenges and barriers to the introduction and sustaining of hospital-based palliative care services. *Palliative Care in California: The Business Case for Hospital-Based Programs* describes the business case for hospital-based palliative care, demonstrating the positive financial impact on hospitals that implement palliative care services.

A more complete description of the entire project may be found in *Palliative Care in California: An Overview of Hospital-Based Programs*. That report includes an exposition of the need for hospital-based palliative care services in California, an analysis of the current state of palliative care in California hospitals, and a comprehensive synopsis of the three reports in the series. All four reports are available at www.chcf.org.

II. Statewide Palliative Care Training Initiatives

OVER THE PAST SEVERAL YEARS, MANY CALIFORNIA hospitals have participated in two major initiatives intended to train and assist in the design and implementation of hospital-based palliative care services. One of those was the California Hospital Initiative in Palliative Services (CHIPS), which served California institutions exclusively. The other is the Palliative Care Leadership Center (PCLC) initiative, a national program that includes a program site in California, in which more than 50 California hospitals have participated.

California Hospital Initiative in Palliative Services

The California Hospital Initiative in Palliative Services (CHIPS) was a two-year (2001–2003), statewide initiative to increase the number of hospital-based palliative care services in California. CHIPS was funded by the Robert Wood Johnson Foundation through the Center to Advance Palliative Care (CAPC), in cooperation with the California Healthcare Association and the California Coalition for Compassionate Care. The CHIPS initiative was a collaboration of palliative care experts at the University of California, San Francisco (Steven Pantilat, M.D. and Michael Rabow, M.D.), San Diego Hospice and Palliative Care (Frank Ferris, M.D. and Charles von Gunten, M.D., Ph.D.) and the California Healthcare Association (Judy Citko, J.D.).

CHIPS recruited hospitals from across California, including urban and rural, academic and community, large and small hospitals, from each region in the state. In year one, CHIPS accepted teams from the 16 hospitals (of 21 applicants) that appeared most ready to implement palliative care services (Cohort 1). The five applicant teams not accepted in year one were among the 22 hospitals accepted in year two (Cohort 2), for a total of 38 hospitals that participated over the two years of the program.

CHIPS: Program Description

The CHIPS program began in February 2001. The application asked each hospital team to identify three individuals, representing at least two disciplines (physician, nurse, nurse practitioner, social worker, chaplain, psychologist, and pharmacist), who would participate in the program. The applicant was asked to identify a team leader and to describe the current state of palliative care

services at the institution. To ensure that each team had administration support, CHIPS further required that each institution's chief operating officer or chief administrator sign the application.

All teams accepted for the program attended a two-day conference at which they were instructed in key components of establishing a palliative care service, including conducting a needs assessment, choosing among models of care, motivating institutional change, understanding business and financial models, and designing a strategic plan. The conference format included brief, large group didactic sessions, each followed by small group sessions. In the small group sessions, each team completed worksheets that formed the blueprint for its palliative care service.

Over the next ten months, each team received ongoing mentoring from an assigned CHIPS faculty member, including regularly scheduled telephone conference calls, emails, and a visit by the faculty mentor to the team's hospital. During the visit, the faculty member typically would meet with the palliative care team, talk with hospital administrators, physicians, and staff, and be present at grand rounds.

Between eight and 11 months after the initial conference, teams attended a 1 1/2 day reunion conference at which they received additional information based on a needs assessment of their service, and shared with other teams and the mentors their successes and challenges. The initial conference for Cohort 2 and the reunion conference for Cohort 1 overlapped to allow teams to learn as

much as possible from one another and to maximize networking opportunities.

CHIPS: Program Impact

In January 2004, the CHIPS program team surveyed the 38 participating hospitals in order to evaluate the quality of the program and its impact.¹ That survey revealed the following data concerning the success of the program with regard to the operation of a palliative care consultation service:

Success of CHIPS

CHIPS achieved a 60 percent success rate—60 percent of hospitals without a palliative care service at the time of enrollment in CHIPS had established one by the time of the follow-up survey.

- Of the 38 participating hospitals, six (16 percent) had a palliative care consultation service prior to enrolling in CHIPS, 16 (42 percent) had a consultation service by the time of the reunion conference (after an average of ten months participation in the program), and 25 (66 percent) had one at the time of the 2004 follow-up survey.
- Among the 32 hospitals that did not have a palliative care consultation service at the time of the initial CHIPS conference, 19 (60 percent) had established a service by the time of the survey.
- Each of the six hospitals that had a consultation service at the time of the initial CHIPS conference still had one at the time of the survey.

A Snapshot of Hospitals Participating in CHIPS

The typical hospital participating in CHIPS was a large, not-for-profit, private hospital in an urban setting, with a staff that included hospitalists. Nearly half of participating hospitals were part of a health care system and two were county hospitals; a minority had an academic affiliation. CHIPS hospitals were distributed throughout California: 19 in Northern California; 14 in Southern California; and five in the central part of the state. Among the 18 hospitals that reported receiving funding for their palliative care service, sources of support included the hospital (16), grants (four), billing (two), and donations (one).

- None of the five hospitals that applied to Cohort 1 but did not participate until Cohort 2 established a palliative care service in the year before participating in CHIPS, but three of the five succeeded in doing so after participating in CHIPS.
- Of the 13 hospitals that did not have a palliative care consultation service in place at the time of the survey, nine (69 percent) had active plans to start one, and, of these, five had plans to begin within six months.
- Overall, 34 of 38 hospitals (89 percent) either had a palliative care consultation service in place or were actively planning to start one by the time of the survey. Hospitals with hospitalists and those in an urban setting were more likely to succeed in establishing palliative care consultation services than the others.

The CHIPS initiative showed similarly positive, if less dramatic, results with regard to the establishment of dedicated palliative care units:

- Only three hospitals (8 percent) had a palliative care unit before the initial CHIPS conference; all three units were still operational at the time of the survey.
- By the time of the reunion conference, there were four units among CHIPS hospitals (11 percent).
- By the time of the survey, there were nine (24 percent) palliative care units.
- Of the 35 hospitals that did not have a palliative care unit at the time of the CHIPS conference, six (17 percent) reported having one at the time of the survey.

Participants gave CHIPS high marks, not only for its direct efforts to help hospitals start palliative care services but also for the program's success in helping participants to network with other hospitals; nearly two-thirds of CHIPS hospitals reported that they had worked with other hospitals to help them develop palliative care services.

CHIPS: Lessons Learned

CHIPS showed that a program of education and mentoring targeted at helping hospitals develop palliative care services can succeed in establishing new services. CHIPS also demonstrated that it takes time for new services to get started. The survey showed that the farther out from the initial conference, the larger the number of hospitals with new palliative care services. The survey conducted 29 months after the initial conference for hospitals in the first cohort showed that some of those institutions still had active plans to begin a service. This delay in activating a service may mean that the length of mentoring in CHIPS was too short.

From their evaluations, it appears that CHIPS participants valued personal contact with faculty members and other participants most highly and found that networking was very helpful. On-site visits were quite expensive because of the time involved for faculty, but they were very highly rated and anecdotally were of very high impact. The reunion conferences provided a chance for teams to share their successes and challenges and to learn from one another. CHIPS participants expressed great interest in continuing to meet regularly, and many supported establishing a network to share ideas, conduct research, and benchmark financial and clinical outcomes. However, due to a lack of funding, no further conferences or networking opportunities were organized through CHIPS.

Palliative Care Leadership Centers

The Palliative Care Leadership Centers (PCLC) initiative is designed to increase the number of hospital-based palliative care services in the United States by teaching hospitals how to design and implement their own services. There are six PCLC sites across the country, one of which is at the University of California, San Francisco. The PCLC initiative was initially funded by the Robert Wood Johnson Foundation through the Center to Advance Palliative Care (CAPC) at the Mount Sinai School of Medicine in New York. In 2006, PCLC continuation funding was provided by the

JEHT Foundation, and for the UCSF PCLC by the California HealthCare Foundation and the Archstone Foundation. The PCLC initiative built on the experience, approach, and curriculum of its California precursor, CHIPS.

PCLC seeks to recruit a broad range of hospitals and encourages applications from hospital-hospice teams. PCLC uses a Web-based application system that asks applicants questions about their institution and current palliative care activities. Participants are encouraged to bring four team members, representing different disciplines, to the PCLC conference. The conference fee is reduced if the team includes a hospital finance person; this discount recognizes the critical role financial analysis plays in the development and sustainability of a palliative care service. In addition, the application requires the CEO or chief administrator of the hospital to sign a letter pledging support for the team's efforts to start a palliative care service. Applicants choose the specific PCLC they wish to visit; they may do so based on geographic considerations and program emphasis (academic, community, hospitalist focus, hospice-hospital partnership focused, cancer center, pediatrics), but each PCLC can work with any type of hospital.

PCLC: Program Description

Once accepted to the PCLC program, a hospital's team attends a two-day conference at its chosen PCLC. Training is accomplished primarily through small group sessions with some didactic presentations focused on the work of developing a palliative care service. The six PCLCs, in conjunction with CAPC, developed a uniform curriculum in palliative care service development that was built from CAPC's existing curricula and materials. This PCLC curriculum consists of eight modules on the following topics: system assessment and mission alignment, clinical models and staffing, financial case and sustainability, measurement, internal marketing, community partnerships, palliative care education, and program implementation. Individual PCLCs may offer electives in addition to the core

curriculum, as well as tours of their palliative care units.

Over the 12 months subsequent to their attendance at the conference, participants have five telephone meetings with a PCLC faculty mentor to monitor progress, troubleshoot problems, provide support, and share information. Many hospitals invite PCLC faculty members to visit their institution to meet with the entire palliative care team, administrators, and medical and nursing staffs. The six PCLCs held a national reunion conference in February 2006 at which participants discussed issues of sustainability and growth, physician billing, measuring clinical and financial outcomes, and operational aspects of a consultation team.

PCLC: Impact in California

Overall, 493 institutions nationally have attended one of the six PCLCs. These include 64 California hospitals, of which 47 attended the UCSF PCLC (see Appendix A). Of the institutions attending the UCSF PCLC, five participated in CHIPS and PCLC.

In July 2005, 6 to 12 months after the first five training conferences, the UCSF PCLC used information collected during mentoring calls to develop outcome data. Of the 57 hospitals included in this evaluation, 74 percent were in the "initial exploration" or "planning" stages regarding palliative care services when they attended the PCLC training conference. Moreover, one-third of respondents had attended their training conference within the prior six months. Despite this combination of early stage development and the brief period that had elapsed since the training, by the time of the mentoring calls:

- Eighty-six percent of teams had recruited a physician champion for their program;
- Sixty-two percent had analyzed cost and utilization data;
- Fifty-three percent had written a business plan;

- Thirty-eight percent had secured initial or increased funding for their programs, and;
- Fifty-three percent were seeing patients.

Unfortunately, PCLC did not collect data on clinical outcomes and therefore cannot report on the quality of care being provided by these new palliative care services. Ultimately, the true measure of success for these initiatives will depend on the number of patients seen and the quality of care provided.

III. Hospital System Palliative Care Initiatives in California

IN ADDITION TO THE CHIPS STATEWIDE AND PCLC national training programs described above, several hospital systems within California have launched their own palliative care initiatives, which represent potentially powerful ways to implement palliative care services in the state. Information about the palliative care services provided below is based on interviews and questionnaires sent to a selected few of California's larger health care systems and providers. Many other systems and hospitals throughout the state undoubtedly are providing palliative care services to their hospitalized patients but the goal of this section was not to be comprehensive but rather to highlight notable efforts to establish palliative care services. The system-wide efforts presented here reflect hospitals with dedicated palliative care services across a broad range of settings, academic and community, urban and suburban, geographic locations, as well as from all payer models—fee-for-service, capitated, managed care. Together, these systems operate 42 percent of California's 400 hospitals. In many cases, these are also health care industry leaders and early adopters whose programs are considered models nationwide. The data presented are from individuals in each system with responsibility for palliative care services where they exist, and from system leaders where they do not.

Catholic Healthcare West (CHW)

Catholic Healthcare West (CHW), headquartered in San Francisco, is a system that includes 42 hospitals, of which 34 are in California. Founded in 1986, CHW is the eighth largest hospital system in the nation and the largest not-for-profit hospital provider in California. Providing palliative care is a part of CHW's overall mission. The vision of palliative care within CHW is to allow all patients to die according to their wishes, and without suffering. As part of this care, a process of advance care planning is provided to all patients. This includes a spiritual assessment by a chaplain, unless declined by the patient. A composite score is given to each hospital based on the extent of advance care planning offered to each patient.

The process of organizational change at CHW used goal-setting and incentives that were tied to executive compensation. For palliative care, the goal was for services to be implemented system-wide by 2004. For the first year of the process, the goal was to

formally plan, budget, and begin implementing an acute, hospital-based palliative care consultation service and/or a dedicated in-patient palliative care service. Planning involved rigorous development of the “structure,” which included a formal business plan with a financial template for the hospitals, staffing budget worksheets to estimate incremental expense, and standardized system-wide indicators with data collection tools. In addition, CHW compiled baseline data to assess resource needs and to estimate service volume.

In year two of the initiative, palliative care teams were constituted, and looked to achieve improvement in two process goals, as well as to establish a baseline for outcome measures. In year three, each hospital measured outcomes. Throughout the process, administrative compensation was tied to achieving yearly goals.

As of 2006, all but three CHW hospitals have palliative care services operating, with the remaining three having services in the planning phase. As new hospitals are acquired, they are required to write a business plan and organize a service within one fiscal year. As to financial impact, CHW elected not to measure costs at the outset, in order to make clear that implementation of the services was borne of the system’s mission, not its economics. However, CHW believes that resource utilization has improved, and intends to collect these data in the future.

CHW’s facilities span the state, covering rural, suburban, urban, and ex-urban communities, and consist of small (fewer than 100 beds), medium (100 to 200 beds) and large (more than 200 beds) hospitals. A breakdown by size and location is presented in Table 1.

Table 1. CHW California Hospitals

SITE	SIZE / LOCATION
Arroyo Grande Community Hospital	Small / Suburban
Aurora Grande Community Hospital	Small / Rural
Bakersfield Memorial Hospital	Large / Urban
California Hospital Medical Center, L.A.	Large / Urban

SITE	SIZE / LOCATION
Community Hospital of San Bernardino	Large / Urban
Dominican Hospital, Santa Cruz	Large / Urban
French Hospital Medical Center, San Luis Obispo	Small / Urban
Glendale Memorial Hospital & Health Center	Large / Urban
Marian Medical Center, Santa Maria	Large / Ex-urban
Mark Twain St. Joseph’s Hospital, San Andreas	Small / Rural
Mercy General Hospital, Sacramento	Large / Urban
Mercy Hospital of Folsom	Small / Suburban
Mercy Hospitals, Bakersfield	Large / Urban
Mercy Medical Center, Merced (2 campuses)	Large / Ex-urban
Mercy Medical Center, Mt. Shasta	Small / Rural
Mercy Medical Center, Redding	Large / Ex-urban
Mercy San Juan Medical Center, Carmichael	Large / Suburban
Mercy Southwest Hospital, Bakersfield	Small / Urban
Methodist Hospital of Sacramento	Medium / Suburban
Northridge Hospital Medical Center	Large / Suburban
Oak Valley Hospital, Oakdale	Small / Rural
Saint Francis Memorial Hospital, San Francisco	Large / Urban
San Gabriel Valley Medical Center	Large / Suburban
Sequoia Hospital, Redwood City	Large / Suburban
Sierra Nevada Memorial Hospital, Grass Valley	Small / Rural
St. Bernardine Medical Center, San Bernardino	Large / Urban
St. Elizabeth Community Hospital, Red Bluff	Small / Rural
St. John’s Pleasant Valley Hospital	Small / Suburban
St. John’s Regional Medical Center, Oxnard	Large / Urban
St. Joseph’s Medical Center, Stockton	Large / Urban
St. Mary Medical Center, Long Beach	Large / Urban
St. Mary’s Medical Center, San Francisco	Large / Urban
Woodland Memorial Hospital	Small / Rural

Each CHW hospital designs its own palliative care service with support from CHW administration. Most hospitals operate a consultation system that typically uses physician support but is not physician-led. Several have dedicated units or swing-bed models. Six CHW hospitals participated in CHIPS, and as part of this initiative, CHW worked with CAPC to help develop processes for palliative care service implementation. Analysis of the impact of this initiative is ongoing.

CHW shares successful practices from one hospital to another. In 2004, it began a voluntary internal collaboration that concluded in September 2005. External faculty helped structure a program in which 13 hospitals chose from a variety of goals, including advance care planning, pain management, symptom management, and the creation of “A Preferred Intensity of Care” form to follow patients from the inpatient setting to skilled nursing facilities.

Kaiser Permanente

Kaiser Permanente is the largest nonprofit health plan in the United States, and one of the largest health plans in California. Divided into northern and southern regions, it forms an integrated health delivery system, with 25 Kaiser Foundation Hospitals in the state, 5,661 staffed beds, and approximately 1.3 million patient days. Kaiser Permanente has instituted a national initiative to provide inpatient palliative care services for all of its members.

Northern California Kaiser is composed of 18 inpatient facilities. Six Northern California Kaiser Hospitals have attended a CHIPS or PCLC training, and 16 (89 percent) either have an inpatient palliative care consultation service or are actively implementing one. Northern California hopes to reach a goal of 100 percent by the end of 2007. Most of Northern California Kaiser’s inpatient services utilize a consultation model with a physician-led multidisciplinary team. All service areas also have hospice services, home health services, and comprehensive complex chronic

conditions case management programs, with skilled nursing palliative care beds in most service areas. Northern California Kaiser aims to create a system-wide palliative care-management paradigm within which patients’ and families’ palliative needs will be coordinated and integrated across many providers and care teams, across many settings in the delivery system, across multiple diagnoses, and longitudinally through time.

Southern California Kaiser is comprised of eleven hospitals, and of these, four (36 percent) have inpatient palliative care services. Most of the inpatient services use a consultation model with a physician-led multidisciplinary team. All 11 hospitals have developed a focus on a home care model of palliative care. It is the overall vision of Southern California Kaiser that any patient or family confronting serious or life-threatening illness should have the opportunity to access palliative care services, regardless of where they are. This access is intended to apply to members who are newly diagnosed through those who are actively dying in any setting—home or inpatient. All service areas have hospice services, home health services, and comprehensive complex chronic conditions case management programs, with skilled nursing palliative care beds available in most service areas.

Sutter Health

Sutter Health is among California’s largest health systems, with a network of community-based health care providers, and 24 locally run acute care hospitals with a capacity of approximately 4,552 staffed beds and 1.24 million patient days. The system also includes physician organizations, medical research facilities, region-wide home health, hospice, occupational health networks, and long term care centers.

While Sutter does not mandate that each of its hospitals have an inpatient palliative care service, there is movement across the system to implement a combination of hospital and home-based palliative care services. Six of its 26 hospitals (23 percent—

equal to the average across California hospitals) have palliative care services, which use a variety of clinician-led models, including a consultation service and/or dedicated bed or unit structure. Services are being brought on-line at a rate of about one per year, with Sutter estimating that the system currently cares for approximately 1,500 inpatient palliative care patients per year. Sutter takes a systems approach that incorporates home care for patients needing palliative care outside of the hospital, through its visiting nurse collaboration, intending thereby to prevent unnecessary admissions and optimizing use of the hospital for very sick or chronically ill patients.

Veterans Affairs Medical Centers (VAMC)

The Veterans Health Administration (VHA) is the largest unified health care system in the country. The VHA, at the highest levels, is convinced of the quality and savings provided by palliative care, and in February 2003 it mandated that all its inpatient facilities establish interdisciplinary palliative care consultation teams under a combined hospice and palliative care (HPC) framework. The term HPC refers to hospice and palliative care as a continuum of comfort-oriented and supportive services provided in the home, community, or inpatient settings for persons in the advanced stages of incurable disease but is not restricted to persons near the end of life. (VHA's definitions of hospice and palliative care can be found in VHA Directive 2002-038.)

Individual VA institutions exercise a great deal of discretion as to the model of palliative care they implement. Although the mandated minimum for each VA facility is a consultation service, there is also a national initiative for dedicated palliative care beds to be established in each VA nursing home. Where a geographic region does not have a VA nursing home, referrals are made to outpatient hospice, or to a contract nursing home that provides hospice care. Under this initiative, in 2003 the Palo Alto VA facility established the first VA-based outpatient palliative care clinic in California.

The Department of Veterans Affairs (VA) divides California geographically into two Veterans Integrated Service Networks (VISN), designated VISN 21 and 22. These two VISNs also cover neighboring states, so the information presented here by VISN is not exclusive to California. California, however, has the vast majority of facilities and patients in these VISNs. VISN 21 includes seven medical center sites with 589 hospital beds and 844 nursing home beds. VISN 22 contains five hospitals operating 1,905 beds including 917 acute care beds and 639 nursing home beds.

Four Northern/Central California facilities fall within VISN 21. In the aggregate, the facilities have more than 40 dedicated palliative care beds, and provide 600 to 700 palliative care consultations annually. Each uses its own model of palliative care, as follows:

- **Palo Alto:** consultation team, dedicated palliative care beds, and outpatient palliative care clinic; also the site of an interdisciplinary palliative care fellowship program (the hub-site for the VA's national program);
- **San Francisco:** consultation team and dedicated beds within a 120-bed SNF;
- **Fresno:** consultation team but no dedicated beds;
- **Northern California:** (medical center in Sacramento, nursing home in Martinez): consultation team and dedicated beds.

There are four Southern California hospitals within VISN 22, as well as a variety of other facilities. Each has a palliative care service, but activity is varied. All are seeing consultations, but not all facilities have the full interdisciplinary team required by the national mandate. Locales in Southern California are:

- **Greater Los Angeles:** (West Los Angeles hospital and two nursing homes at West Los Angeles and Sepulveda);
- **Long Beach:** (hospital, nursing home);

- **Loma Linda:** (hospital, nursing home);
- **San Diego:** (hospital including skilled nursing beds).

In the main, VA programs are physician-led, but there is variation in team leadership across facilities. Unique to the VA, nurse practitioners outnumber physicians on palliative care services. At Long Beach, the program is nurse practitioner-led for day-to-day inpatient consultation with overall management by a physician, and monitoring by a case manager who oversees the care plan. Two programs are physician-led, and two are social worker-led. Within each VISN is an accelerated clinical training (ACT) mentor who is responsible for initiating and promoting palliative care within the region.

County Hospitals

Few county hospitals in California have dedicated palliative care services. The 22 county hospitals in California operate a total of 9,227 licensed beds. Total staffed beds number 6,547; 63 percent of the beds are acute, with annual discharges of 252,411. Of these 22 hospitals, however, research for this report was able to confirm only four (18 percent) with dedicated palliative care services: Alameda County Medical Center/Highland Hospital in Oakland; Santa Clara Valley Medical Center (SCVMC) in San Jose; Los Angeles County/USC Medical Center in Los Angeles, and Laguna Honda Hospital and Rehabilitation Center (LHH) in San Francisco. The lack of palliative care services in county hospitals is of particular concern because so many of the patients who use these facilities are without insurance, and are further disenfranchised by lack of access to this valuable service.

The Laguna Honda facility's palliative care service is worthy of special mention. LHH Hospice was founded in 1988 in San Francisco's county-run nursing home. In addition to hospice services, its multi-disciplinary team cares for patients in a 25-bed, dedicated palliative care unit. LHH Hospice accepts any San Francisco resident who requires

skilled nursing services, and who requests palliative or hospice care, without regard to expected survival.

An encouraging note is that San Francisco General Hospital recently completed PCLC training at UCSF and has initiated the planning stages for palliative care services. Los Angeles County, an affiliate hospital of the Keck School of Medicine at USC, recently started a palliative care consultation service and is the only county hospital in the enormous Los Angeles region to have such a service.

University of California Medical Centers

Collectively, the five UC medical centers operate 3,042 staffed beds, and account for 781,456 inpatient days. Five of the eight have dedicated palliative care services.

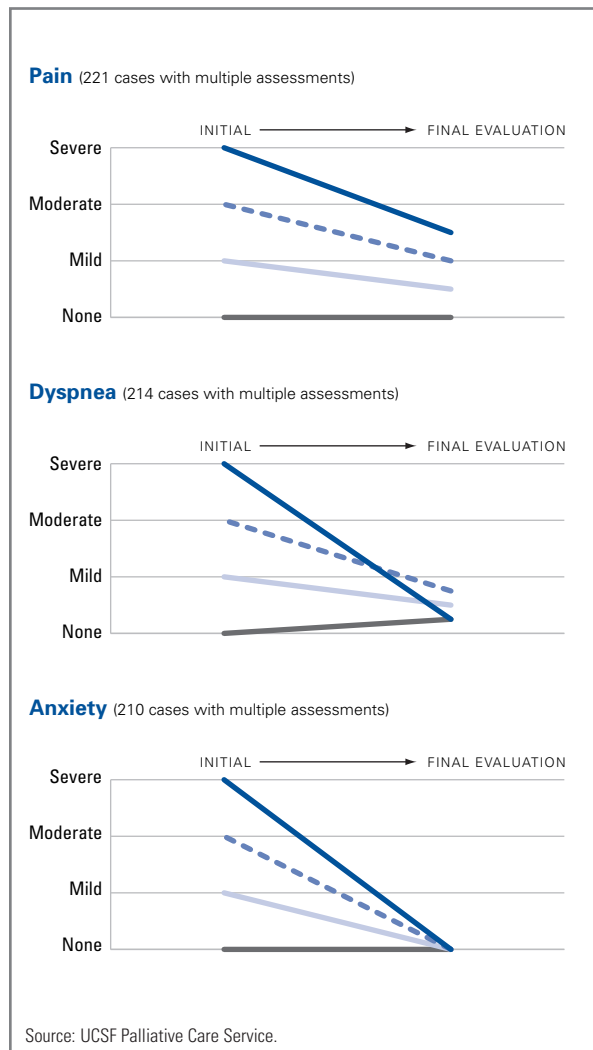
University of California, San Francisco

Established in March 1999, the UCSF Palliative Care Service (PCS) was one of California's first hospital-based palliative care services. Its physician-led, interdisciplinary palliative care team operates exclusively as a consultation service, and becomes involved in patient care at the request of an attending physician. The consultation team consists of eight physicians (five of whom are board certified in palliative medicine), nurses, a social worker, a chaplain, a pharmacist, and volunteers, all trained in palliative care. It also includes a fellow, residents, and medical students. Consultation requests are fielded by the PCS attending physician who is available by pager, 24 hours a day, seven days a week. As appropriate, patients can be transferred to the Comfort Care Suites, a two-bed inpatient swing-bed palliative care unit.

In its first seven years, the UCSF PCS cared for more than 1,500 patients who were referred to the service by 191 attending physicians. The service admitted 102 patients in its first year, and saw volume increases of 36 percent, 50 percent, and 25 percent (to 261 patients) over the next three years. Volume held steady at about 250 patients a year in

service years four to six but grew again by 30 percent to 351 patients in year seven, and is projected to grow by another 30 percent to 450 in year eight. Data collection by the PCS has shown impressive improvements in symptoms for patients cared for by the service (see Figure 1), as well as increases in family satisfaction, and decreased costs of care.

Figure 1. Symptom Control for UCSF Palliative Care Service Patients



University of California, Irvine

The UCI Medical Center, a 460-bed university hospital in Orange County, offers a full scope of acute and general care services. The facility’s palliative care consultation service sees about 15 consults per month, with most referrals coming from the general medicine services, some also from neurology and a very few from pediatrics. The service was initiated six years ago as part of UCI’s compliance with the state legislature’s mandate to provide medical students with curriculum in end-of-life care.² UCI uses an integrated model, that is, with no dedicated palliative care team, but with a board-certified geriatrician specializing in palliative care as the service chief and an as-needed staff drawn from nursing, social work, and chaplaincy. One result of this model is that palliative care practice is dispersed throughout the institution. UCI also has a palliative medicine fellowship, and plans to hire an additional physician faculty member to the palliative care service, as well as to start an outpatient palliative care clinic in its cancer center. UCI was recognized as a Better Performer in the University HealthSystem Consortium’s (UHC) 2004 Palliative Care Benchmarking Project.

University of California, San Diego

The UCSD multidisciplinary palliative care service operates in collaboration with San Diego Hospice & Palliative Care (SDHPC—see description below). The service sees a projected 500 consultation patients yearly and refers to all 12 hospice programs that serve the county. SDHPC is the largest of these referral agencies, with approximately 5,000 patients under the program’s care through hospice or case management. The staffing of the UCSD service draws from both institutions: SDHPC provides the physician (an attending and fellow), and UCSD provides the nurse practitioner and social worker. Billing is on a fee-for-service basis, with the fellow a part of SDHPC’s fellowship program. UCSD patients may be transferred to SDHPC’s 24-bed specialty hospital.

Based on the success of its pilot program, the UCSD service will expand to two more campuses, the 120-bed Thornton Hospital and 500-bed Hillcrest Hospital. When fully operational, it is anticipated that volume and geography will force each facility to have its own team. At the Thornton campus, the multidisciplinary consultation team of physician, nurse practitioner, and a social worker will see cancer patients at UCSD's Moores Cancer Center in both outpatient and inpatient settings.

University of California, Davis

UCD has adopted the World Health Organization's definition of palliative care, that is, care delivered throughout illness even if not associated with end of life. Hospice is the underpinning of the program, but UCD also has a physician-led interdisciplinary inpatient pain service and consultation team that provides palliative care, but maintains no dedicated beds. The inpatient pain and palliative care consultation service is available around the clock for all services in the institution, and will see any patient suffering from any type of poorly controlled symptom.

UCD's efforts are clinician-led. The service is staffed by an attending physician, a fellow, a pharmacist and a nurse specialist. On a system level, palliative care is promoted through specifically targeted physician and nurse leaders who work with their programs to advance palliative care. The pain and palliative care consultation service has been in place since 1999, and sees approximately 150 to 200 cases per year. In addition, in conjunction with the institution's innovative Simultaneous Care Project, the consultation service provides palliative medical services to UCD Cancer Center patients who choose to participate in experimental cancer clinical trials, which usually renders them ineligible for hospice services.

University of California, Los Angeles

The mission of UCLA's Palliative Care Team is to partner with patients and their families to help define and achieve realistic goals to optimize

quality of life. Since February 2002, a physician-led interdisciplinary team of health care professionals, in partnership with patients' medical care teams, has provided coordinated medical, nursing, social work, and spiritual care. Palliative Care at UCLA also includes nutritional, physical, and occupational therapy. The team sees approximately 300 patients per year and is growing yearly.

There are two UCLA hospitals, one a community-based hospital in Santa Monica, the other an academic hospital in Westwood. The inpatient service at the Santa Monica hospital admits to a medical/surgical ward. With few exceptions, palliative care patients are admitted to the same ward where nursing staff has special training in palliative care and receives ongoing training with the ward's nursing supervisor. The service does not have designated beds, but patients are nearly always assigned a single room. The team also provides consultation services at both UCLA hospitals. Admissions to the Santa Monica service come from home, clinic, emergency room, and transfers from the Westwood campus.

Other California Hospitals and Systems

San Diego Hospice & Palliative Care, San Diego, CA (SDHPC)

SDHPC provides comprehensive physical, emotional, and spiritual care for adults, children, and infants faced with an advanced or life-limiting illness. SDHPC employs 16 full-time physician faculty members and 11 fellows. In addition, there are approximately eight nurse practitioners, 30 social workers, 200 nurses, and 12 chaplains. Its average daily census is 650 home care hospice patients and 150 AIDS case management patients. It maintains two inpatient facilities totaling 36 beds.

In addition, SDHPC makes available a palliative medicine consultation service to assist community physicians. Upon request, a trained palliative medicine specialist will make patient visits in private homes, residential care facilities for the elderly, acute

care hospitals, or skilled nursing facilities, or will see outpatients at the SDHPC campus, to assess complex symptoms and to discuss findings and suggestions with the requesting physicians. These consultations are available for all patients, regardless of age, and are not limited to those patients considered hospice-appropriate.

Tenet Hospitals

Formal palliative care services have not yet been integrated into most of the Southern California Tenet hospitals. One initiative to develop these services exists at the Norris Cancer Hospital of the Keck School of Medicine at the University of Southern California. The Norris Cancer Hospital program is a consultation service administered under the department of anesthesiology. It features a full interdisciplinary team and provides support for cancer patients upon referral. The consultative team's main focus is on pain and symptom management.

Adventist

Adventist Hospitals is a faith-based organization that operates 15 hospitals in California. Of these, two have active palliative care consultation services: Loma Linda University Medical Center (which participated in CHIPS and the UCSF PCLC) and San Joaquin Community Hospital in Bakersfield (which attended the UCSF PCLC).

Daughters of Charity

One hospital of the seven-hospital Daughters of Charity system, O'Connor Hospital in San Jose, attended the UCSF PCLC and has successfully launched a palliative care consultation service.

Sharp

The Sharp System operates seven acute care hospitals in the San Diego area. At Sharp Grossmont Hospital, there is a home-based hospice with a small residential unit of six beds and a nurse-led palliative care consultation service. Recently, San Diego Hospice & Palliative Care has been asked to provide a physician member to work as a consultant with Sharp Community Medical Group, a large

physician-group practice associated with the Sharp system.

Scripps

Scripps Health System operates five hospitals in the San Diego area. A partnership between San Diego Hospice & Palliative Care and Scripps's 500-bed flagship teaching hospital, Mercy Scripps, operates a multidisciplinary consultation service that sees 40 consultation patients per month. Negotiations are under way between San Diego Hospice & Palliative Care and Scripps Green Hospital to implement a pain and palliative care service.

IV. California Initiatives in Clinician Training

IN RECENT YEARS, CALIFORNIA HAS SEEN INITIATIVES NOT only in the establishment of hospital-based palliative care services but also in the training of clinicians who will be called on to staff those services as they continue to proliferate throughout the state. These initiatives include physicians, nurses, and other professional clinical and support staff members, at levels of initial certification training and continuing education.

Initiatives in Physician Training

Recently, a number of initiatives have greatly improved the potential for training medical students in the basics of palliative care, raising the bar for all practicing physicians and creating a cohort of highly trained palliative care physician specialists. California's five state and three private medical schools are making efforts to expand palliative care training for both pre-clinical and clinical students. Highlights of selected programmatic features are provided in Table 2 on the following page. Although many of the curricular offerings are elective, some palliative care content is now incorporated into coursework required of all students.

These efforts at California medical schools are at the forefront of those undertaken nationally. Three specific efforts deserve special mention. Research at the University of California, San Francisco Medical School has begun to address not just the limited formal curriculum, but also the "hidden curriculum" around end-of-life care and institutional culture. Also, a collaboration of California medical schools has included a case of a woman receiving the news of breast cancer as one of the standardized patient scenarios used to evaluate third-year student performance. Finally, in 2005 state leaders in palliative care education launched a University of California-wide project, based at the University of California, Davis and supported by a five-year grant from the National Cancer Institute of the National Institutes of Health, to develop, implement, and evaluate a Web-based end-of-life care curriculum at all five state medical schools.

Table 2. Curricular Offerings in Palliative Care among Selected California Medical Schools

SCHOOL	OFFERINGS
University of California, Davis	<ul style="list-style-type: none"> • Medical student and resident rotations in palliative care at the UC Davis Cancer Center, hospice programs, and pediatric hospice program • Required medical student home visits with frail elderly • The doctoring program (UCD and UCLA) teaches aspects of doctor-patient communication skills to medical students incorporating ethics, medical decision-making, and evidence-based medicine • Internal medicine and family medicine residency involvement with palliative care aspects of geriatrics, cancer care, and hospice care through the UC Davis Home Health and Hospice program
University of California, Irvine	<ul style="list-style-type: none"> • First-year students in a patient-doctor course are introduced to palliative care and hospice, including a case-based discussion with presentations by different team members and a family member • A “selective” five-hour workshop teaching communication with dying patients and families • Longitudinal hospice rotation for internal medicine residents • Hospice home visits as part of geriatrics rotations for family medicine residents
University of California, Los Angeles	<ul style="list-style-type: none"> • Rotations with the palliative care service (inpatient and outpatient) for medical students and residents • Seminars on end-of-life care by the Division of Geriatrics • The doctoring program (see above under UC Davis)
University of California, San Diego	<ul style="list-style-type: none"> • First-year “Patient and Physician” course includes palliative care (about half of first-year students make a home visit with hospice staffer) • Third-year students spend a day per week at the hospice program during a required internal medicine clerkship³ • Four UCSD residency programs (internal medicine, family medicine, pediatrics, and psychiatry) require their residents to rotate for up to a month with the inpatient and home services of San Diego Hospice & Palliative Care • The Center for Palliative Studies (CPS) at San Diego Hospice & Palliative Care sponsors required palliative care curricula and rotations for students and for eight residency programs: the UCSD programs in internal medicine, family medicine, psychiatry, and pediatrics; Scripps Mercy internal medicine; Scripps Green internal medicine; Camp Pendleton family medicine; and Balboa Naval Hospital internal medicine. • CPS offers one of the largest accredited palliative medicine fellowships in the world, has programs for physicians in practice, and has relationships with schools of nursing, social work, and a variety of other disciplines
University of California, San Francisco	<ul style="list-style-type: none"> • Required second-year “Foundations of Patient Care” course includes an entire quarter devoted to end-of-life care content, including a four-hour end-of-life preceptorship with a clinician involved in hospice, palliative care, or pain management • Required third-year “Intersessions” course, with small groups sessions on advance directives, physician-assisted suicide, and curative treatment withdrawal, based on students’ clinical experiences • Required standardized patient exercise focused on advance directives during the third-year medicine clerkship • Elective rotations for students and internal medicine and family medicine residents in hospice, long term care, and palliative care • Palliative care topics integrated into a required outpatient experience for all medicine interns • Elective in “Hospice and Palliative Care” for first- and second-year medical students, nursing students, and pharmacy students • A fellowship in palliative medicine
Stanford University	<ul style="list-style-type: none"> • Required first- or second-year student four-hour workshop on key aspects of palliative care • Required third- or fourth-year palliative care, ethics, and hospice clerkship • A minimum of a half-day field experience with hospice staff • Required home hospice house call for students • Month-long, full time, palliative care elective for students and residents • Palliative Care topics integrated into the core curriculum for interns and residents • Required geriatrics rotation for interns, including one half day in the palliative care inpatient unit at the VA Palo Alto Health Care System • The VA Palo Alto Health Care System co-sponsors an inter-professional (MD, nurse practitioner, social work, psychology, and chaplaincy) one-year, clinical palliative care fellowship

Physician Palliative Care Experts and Leaders in California

California physicians are seeking and receiving certification as specialists in palliative care from the American Board of Hospice and Palliative Medicine.⁴ Presently, 223 California physicians have received their certification. A number of California physicians have achieved national prominence as leaders in palliative care. The Soros Foundation Project on Death in America identified ten California physicians as faculty scholars, out of 71 scholars nationally.⁵

In addition to these initiatives in medical student and resident training, California is host to significant innovations in continuing medical education and palliative care expertise for physicians. California is among the leaders nationally in requiring by law that all licensed physicians receive 12 hours of continuing medical education in pain management and palliative care. The Stanford Faculty Development Center facilitator-training course in end-of-life care, held from 2000 to 2002, trained 17 end-of-life care facilitators. This curriculum is available online (www.epec.net). The San Diego Hospice & Palliative Care and others sponsor the Education in Palliative and End-of-life Care (EPEC) program—a landmark continuing physician education program in palliative care.⁶ In the first eighteen months of the project, 555 EPEC trainers reached 120,000 health care professionals. Since that time, another 1,000 physicians have been trained. The EPEC curriculum has become the basis for curricula for medical schools, residency and fellowship training programs, and other health professions education programs, establishing a national standard for basic education in the field.

Initiatives in Training and Professional Development of Other Clinicians

Nurses: A nursing training program called the End-of-Life Nursing Education Consortium (ELNEC), developed at the City of Hope Medical Center (COH) in Duarte, has become the leading national program providing end-of-life care training for nurses. More than 2,445 nurses from all 50 states have received ELNEC training. Many of these report sharing their training with other nurses.^{7, 8} California is among the top four states nationally in number of ELNEC trainers.

Nurse Palliative Care Expertise and Leadership

In California, there are 587 nurses certified by the National Board for Certification of Hospice and Palliative Nurses (of 9,066 nationally).⁹ Three California nurses were identified by the Soros Foundation Project on Death in America as faculty scholars.¹⁰

In addition to the ELNEC program, COH has conducted numerous palliative care educational programs over the past 15 years. Its annual Pain Resource Nurse (PRN) training program is a three-day intensive program that trains 100 to 150 nurses. COH also conducted a National Cancer Institute (NCI) funded project, Home Care Outreach for Palliative Care Education (HOPE). The HOPE project included teams from home care agencies and was intended to improve end-of-life care in non-hospice home care agencies.¹¹ Another successful project conducted by the COH team and funded by the NCI addressed improved cancer pain education for patients and professionals. Yet another significant effort focused on cancer care has been the “Disseminating End of Life Education to Cancer Centers” (DELEtCC) project,¹² a five-year program that included teams from 201 cancer centers, including 44 from California, with the goal of improving palliative care in cancer settings.

Pharmacists: Increasingly, pharmacy schools are expanding their curricular offerings in palliative care, and a few pharmacy residents have begun seeking post-graduate education in palliative care. UCSF presents curricula in end-of-life care to students in its clinical pharmacy program, and offers an advanced practice pharmacy residency in pain and palliative care.

Social workers: Although there is no standard curriculum or training for social workers regarding palliative care, social work palliative care competencies are being proposed by leaders in the field.¹³ For their work in social work aspects of palliative care, nine California social workers have been recognized with Social Work Leadership Development Awards by the Project on Death in America.¹⁴

Chaplains: California is home to 20 of the 350 Association for Clinical Pastoral Education, Inc. (ACPE) accredited CPE centers. One of the largest CPE programs nationally, the University of California, San Francisco, has led the country with focused training on caring for people at the end of life.¹⁵

V. Innovations in Implementation and Organization

HEALTH CARE ORGANIZATIONS ACROSS THE NATION have designed innovative strategies for the organization and implementation of palliative care services. These innovations, while not subjected to rigorously controlled trials, have worked, and continue to work, across a variety of settings. Information about them for this report was collected from leaders in the field of palliative care across the country, including those at CAPC, among the six PCLC sites, from the Promoting Excellence in End-of-Life Care program's Innovative Models and Approaches for Palliative Care, from the University HealthSystem Consortium (UHC), and from those recognized by the American Hospital Association's Circle of Life program.

The innovations cover a broad range of palliative care issues, including structural and leadership models, sources of motivating factors in program development, geographic and institutional settings, and unique responses to particular clinical or demographic needs. Following is a selection of program descriptions that cover a spectrum of practice settings and organizations. (These descriptions are based upon information provided by the programs themselves; their features have not been independently investigated by the authors or by CHCF.)

For contact information regarding any of the services or programs described below, see Appendix B.

Nurse-led service in a small hospital—

COMMUNITY HOSPITAL OF THE MONTEREY PENINSULA, MONTEREY, CA

The Community Hospital of the Monterey Peninsula (CHOMP) developed a nurse consultant-based palliative care service that operates with a medical director who is board-certified in hospice and palliative care. Nurse consultations are initiated by physician order, increasingly from hospitalists. Other members of the team come from those hospital staffers who were previously involved with the patient and may include a social worker, chaplain, pharmacist, clinical nurse instructor, and discharge planner.

Nurses, available seven days a week from 8 a.m. to 5 p.m., do not provide “hands-on care” but work with families and patients to establish goals of care and discuss end-of-life issues, then make recommendations for symptom management. The team has drafted

comfort care orders, which it uses to tie into the electronic medical record system being employed at the hospital.

The service reports an average daily census of 12 to 15 patients. A significant feature of the service's success has been the team's marketing strategy that included high visibility in any routine patient-care event at the hospital. For example, the team attends weekly oncology rounds, daily ICU rounds, weekly medical-surgery rounds, and weekly radiation oncology rounds. The team also offers at least two continuing medical education presentations a year on palliative and end-of-life care, and it educates the hospital's nurses one by one.

Collaborative service integrating staff from a large, community-based hospice program on-site with the staff from a comprehensive cancer center—PROJECT SAFE CONDUCT, IRELAND

CANCER CENTER, CLEVELAND, OH

Project Safe Conduct is composed of the Ireland Cancer Center of Case Western Reserve University/University Hospitals (ICC), an acute care comprehensive cancer center, and Hospice of the Western Reserve (HWR), a large community-based hospice program. The project's overall goal is to create a seamless transition from curative to palliative to end-of-life care for patients and families by bringing palliative care principles into the acute-care setting, and involving patients and families at an early stage in decision-making.

The project's safe conduct team (SCT) is composed of a nurse practitioner, social worker, and spiritual counselor. The SCT works much the same as a hospice team and is integrated into the existing oncology teams that treat lung cancer patients in the ambulatory clinic. The SCT also follows patients in the acute care setting. A psychologist and pain specialist are consultants to the team and patients; the oncologist is also a member of the team for the individual patients he or she follows. Involvement of spiritual care through SCT was initially very foreign

in the acute care setting but over time has become an accepted and integral part of the team.

One of the project's significant innovations, and something to which great attention was paid from the outset, was the melding of the two very different cultures of hospice and acute cancer care. ICC physicians and key clinical staff members attended a half-day retreat to learn about safe conduct prior to the program's implementation, and members of the SCT observed at ICC by "shadowing" cancer center staff members during chemotherapy administration, physician visits, and radiation therapy. The success of this melding of the two cultures has been demonstrated by significant changes within ICC, among which are:

- Dramatic improvement in pain management for patients in the project as well as other patients in the ICC;
- Pharmacological interventions now correspond to a pain care path created by the project;
- A pain flow sheet was created and is used on patients' charts to assess and monitor pain;
- Formalized family conferences regarding options and level of care are taking place with all patients;
- Physicians are becoming much more comfortable discussing options when treatment fails; and,
- Eighty percent of patients now die with hospice support as compared with 13 percent prior to the program.

Multidisciplinary consultation team in a large VA network—VETERANS INTEGRATED SERVICE

NETWORK (VISN) 3, NY/NJ

The Veterans Integrated Service Network (VISN) 3 Palliative Care Program is composed of five VA Medical Centers: Bronx; New York Harbor Healthcare system; Northport; Hudson Valley Healthcare system; and New Jersey Healthcare system, with eight separate sites. Its palliative care consultation team (PCCT) at each of the eight sites extends the scope of services available to patients

and families and seeks to establish a single standard for end-of-life care throughout these facilities. This endeavor has emphasized developing professional documentation templates and guidelines to ensure that all critical areas of care and needs are assessed and documented. All the PCCTs use a standardized palliative care electronic consultation form for the initial evaluation by the PCCT physician or nurse practitioner. A separate electronic palliative care psychosocial assessment form is completed by the social worker or psychologist, and a spiritual assessment form is completed by the chaplain. The teams monitor processes and outcomes of care in several ways, including the activities of the PCCTs on the VISN report card and through interviews with family members after the death of their loved one.

The Palliative Care Program closely collaborates with the National VA Hospice and Palliative Care Initiative, the Bronx-New York Harbor Geriatric Research Education and Clinical Center (GRECC), and the New York/New Jersey Hospice Veteran Partnership.

Virtual inpatient unit, academic hospital—

FROEDTERT HOSPITAL, MEDICAL COLLEGE OF WISCONSIN, MILWAUKEE, WI

Froedtert Hospital, the main teaching facility for the Medical College of Wisconsin, began a “virtual” inpatient unit in 1999 to complement its palliative care consultation service. The unit is a 24-bed general medicine ward for which palliative care has first call of beds. All nurses on the unit have received palliative care training and several have board certification. There is an interdisciplinary team approach to patient care with twice-weekly team meetings. The unit offers special amenities for palliative care patients and families in terms of space and services. As part of the hospital’s teaching mission, patients who come to the unit stay on the medical team of origin, but the palliative care service has order-writing privileges and coordinates care.

The virtual aspect of the unit gives the service flexibility in care options, but does not impose the burdens of needing to “fill beds” or manage the nursing and staffing logistics, as is the case in a fixed-bed palliative care/hospice unit. This virtual unit fits the service’s needs and has been successfully adapted at other teaching and community hospitals. The Froedtert palliative care consultation service was recognized as a “better performer” in the 2004 UHC Palliative Care Benchmarking Project (see box on page 23).

Nurse-physician co-led team, academic medical center—

THOMAS PALLIATIVE CARE SERVICES, RICHMOND, VA

At Thomas Palliative Care Services at Virginia Commonwealth University’s Massey Cancer Center, the multidisciplinary palliative care consultation team is co-led by a nurse-M.D. partnership, and has dedicated beds, as well as an outpatient clinic. The team has developed algorithms for symptom management, as well as other aspects of clinical care, and has created marketing brochures and policy documents that have allowed them to obtain referrals from all of the other services at their institution. The team conducts education programs in every division on a yearly basis. Every medical student is introduced to palliative care during course work, and palliative care electives are offered to interns and residents regardless of the rotation they are on. Education is also conducted in the community via town forum presentations. Recently, the program received a state of Virginia grant that provides the opportunity for health care providers from other Virginia institutions to shadow the Thomas service. In addition, the service undertakes legislator education.

UHC Palliative Care Benchmarking Project

In 2004, the University HealthSystem Consortium (UHC) conducted a palliative care benchmarking project to help its members better understand how to identify patients who would benefit from early referral for palliative care services and to evaluate performance in delivering care to patients with terminal illnesses or chronically deteriorating conditions. As part of its work, the benchmarking project identified certain individual palliative care services as a “better performer,” which means that the service scored above the median level on a number of benchmarks UHC determined are critical to delivering high quality palliative care.

The benchmarking project’s key performance measures were:

- Pain assessment within 48 hours of admission
- Use of numeric pain scale
- Pain relieved or reduced within 48 hours
- Bowel regimen with opioid administration
- Dyspnea assessment within 48 hours of admission
- Dyspnea relieved/reduced within 48 hours of admission
- Documentation of patient status within 48 hours of admission
- Psychosocial assessment within four days of admission
- Patient/family meeting within one week of admission
- Plan for discharge disposition documented within four days of admission
- Discharge planner arranges services required for discharge

Out of its assessment of programs, and in particular based on site visits with better performers, the project identified six critical success factors:

- Patient-centered philosophy
- Committed physician champion
- Multidisciplinary team approach
- Active support of senior leadership
- Effective communication strategies
- A culture of quality improvement

For more information about the benchmarking project, see the University HealthSystem Consortium Web site: www.uhc.edu/home.asp.

Palliative care delivery to hard-to-reach populations, university-based program—

SIMULTANEOUS CARE PROJECT, CENTRAL VALLEY, CA

Researchers at UC Davis Medical Center and the West Coast Center for Palliative Education, Sacramento, through the Simultaneous Care Project, are expanding and improving the level of palliative care available to people in three isolated, rural areas in California—Colusa, Tuolumne, and Plumas counties—as well as within the state’s women’s prisons, target populations dissimilar in many ways but each lacking adequate access to palliative or hospice care.

Within this project, palliative care experts train teams of health providers to work in the rural counties and to use teleconferencing links to UC Davis physicians for immediate assistance in the care of dying patients. Using remote television, UC Davis physicians view patients and offer suggestions for care. Additionally, health care workers in the women’s correctional institutions receive palliative care training to provide better care for female inmates who are dying. Another component of the program provides palliative medical services to UC Davis Cancer Center patients who choose to participate in experimental cancer clinical trials,

which usually make them ineligible for hospice services.

Hospital-hospice partnership across multiple sites — CAROLINA HEALTHCARE SYSTEM, CHARLOTTE, NC

In Charlotte, North Carolina, bedside nurses at four hospitals in the Carolina Healthcare System (CHS) initiated efforts that ultimately led to the creation of a multi-site palliative care consultation service. In January 2004, CHS, with four acute care facilities, two long term care facilities, and a home health agency, formed a working partnership with Hospice and Palliative Care Charlotte Region (HPCCR), itself a consortium of hospice programs, to begin a collaborative effort to bring a palliative care consultation service to each hospital. The partnership drew on CHS's expertise in acute care, and on HPCCR's end-of-life care leadership in the community, and extended invitations to every department and floor nursing staff in the facilities. Structurally, the partnership decided to integrate HPCCR's program into the hospital, using its staff.

A committee structure governs the service. The system for obtaining referrals is illustrative. With membership from each institution, the consultation policy committee developed a trigger, or consult, sheet tool. The education committee taught the hospital staffs how to use the tool, then assigned a committee to oversee its implementation. Each hospital, in turn, uses its own education committee to conduct on-site education and implementation of the tool. The consultation teams themselves are physician- and nurse practitioner-led, each site having its own team. Patients are mandated to be seen within 48 hours, but most are seen within several hours.

The results from this collaboration have been dramatic. The program has reached a penetration rate of 1.5 percent of all Medicare discharges for all four acute care hospitals. The partnership reported a \$1.4 million savings for CHS for 2005, calculated according to its analysis of length of stay and

associated decreases to charges and costs in each facility.

Community hospital with a replicable clinical pathway for palliative care — HOAG MEMORIAL

HOSPITAL PRESBYTERIAN, NEWPORT BEACH, CA

Hoag Memorial Hospital Presbyterian, a 2005 Circle of Life Award Winner, is a 511-bed, not-for-profit, acute care hospital in Newport Beach, California. Hoag Memorial has created a sustainable model that introduces supportive and palliative care as a routine part of treatment for the seriously ill. The model has been replicated at a dozen other hospitals. As described in the award, the program created a supportive care initiative that established a clinical pathway with a pre-printed order set and nursing plan of care for actively dying patients and their families. The palliative care team is interdisciplinary, with leadership by a pulmonologist and the ethics committee chair. A social worker is the only full-time paid position, with plans for a pain resource nurse to become part of the team's full-time staff. The team operates on a consultation basis. Using a triage model, the social worker, often in conjunction with a nurse, makes an initial global needs assessment across family/social, symptom management, and spiritual domains, and calls in the appropriate team members. The pathway is in use in more than one-third of hospital deaths.

Multidisciplinary program to bring palliative care to remote communities —

HELPING HANDS PROGRAM, BRISTOL BAY, AK

The Helping Hands Program is a village-focused, culturally sensitive, volunteer and primary care program, combined with services from a regionally based physician and home health nurse, that delivers multidisciplinary palliative care and end-of-life services to remote communities in Alaska. This project of the Bristol Bay Area Health Corporation, also called Ikayurtem Unatai ("Helping Hands" in Yup'ik), responds to the needs of people dying in isolated, rural communities in southwest Alaska. For many Alaska Natives, living in the rugged land of their ancestors surrounded by natural beauty adds

Scalable Programs for Small Hospitals from the PCLC Curriculum Module

(used by permission from CAPC)

Innovative approaches in palliative care programming are required for a small hospital or for a community hospice or home care agency working with a small hospital. Models such as dedicated palliative care consult teams or specialized units common in large urban settings may not appear feasible; however, palliative care programs are scalable and existing resources can be enhanced to develop creative models to meet community needs. Small hospitals are those with fewer than 120 beds (excluding obstetrics and behavioral) and approximately 12,000 admissions. Community-based hospice and home care programs are often essential partners in developing a palliative care program. A sampling of program models follow:

One small community hospital has created a 0.8 FTE APRN who will address both pain management (including non-palliative care patients) and palliative care. The vice president for medical affairs serves as the collaborative physician and representative to the medical staff. A hospitalist participates on the hospital's palliative care advisory committee. Unit social workers and chaplains participate in the assessment and care planning for patients referred to the palliative care nurse.

A 28-bed hospital that houses a multi-specialty clinic has oncology and internal medicine clinic nurses identify patients for a palliative care consultation. Family conference time allows a chaplain, nurse, and physician to meet with the patient and family about goals of care, surrogate decision-making, and future plans for hospitalization or admission to hospice. The integration of an electronic medical record is used to identify patients with certain diagnoses or repeat admissions and to document care discussions available to providers if the patient is seen in the ER or admitted to the hospital. Since there is no palliative care nurse at this time, the hospice nurse case manager is consulted for symptom management issues for any patient regardless of enrollment in hospice. An internal medicine physician has championed this process with his colleagues.

In 1989, the VCU Massey Cancer Center began the Rural Cancer Outreach Program to provide state-of-the-art cancer care to patients in the rural, medically underserved, poorer sections of Virginia that had the highest cancer mortality time trends. Through this rural outreach program, Massey has been working with a small rural hospital for over 15 years. This hospital recently attended Massey's palliative care leadership training session. An internist from this hospital joined its palliative care fellowship program and will complete her fellowship while leading the initiative. The community hospital is providing the physical space for the program, marketing, administration, nursing, physical therapy, occupational therapy, and social work. In addition to providing supervision of the fellow, Massey is mentoring the entire hospital palliative care team through the palliative care program's development.

A community hospital has charged two R.N. case managers—one from cardiology and one from oncology—to lead its palliative care program. The case managers will identify patients who would benefit from palliative care services, and provide the initial triage of patient chart and patient/family interview. Once a patient and the palliative care issues are identified, the case manager notifies the dedicated physician for the team. Other interdisciplinary team members are unit-based.

A community hospital had a dedicated interdisciplinary palliative care committee committed to beginning a palliative care program despite a lack of identified nursing resources. The committee designed a process to use the expertise of the current staff and to focus on ICU patients, where there were many situations in which palliative care could have made a profound quality and financial impact. Together with the charge nurse, the ICU social worker began to review all ICU patients to identify patients with 3 to 5 day length of stay and who had failure of one or more organ systems. The patients' physicians were contacted, and the staff offered to arrange family conferences to review the situation, prognosis, treatment, and future care options. The nurse, social worker, chaplain, and physician attend, and the conferences include the patients whenever possible. Outcomes have included identification of a surrogate decision maker, change in code status, decision about future surgeries and decisions about future hospital admissions. These conferences can also be held for medical surgical patients with similar criteria or patients with recent multiple admissions. In skilled nursing facilities, these can be held on admission.

quality and meaning to life. But before the Helping Hands Program, in order to receive medical care at the end of life, many Alaska Natives were forced to leave their villages for hospitals in Dillingham or Anchorage. They often spent the last days of their lives away from relatives, friends, and their community, putting them at significant risk for added suffering.

With the Helping Hands Program, Alaska's community health aides serve dying patients in 34 southwestern Alaska villages, while receiving consultation and direction via radio or phone from medical staff in Dillingham. The project accepts patients of all diagnoses and ages, within a two-year window of anticipated death. The project provides curative and palliative care simultaneously from a team of nine physicians, two nurses, a volunteer coordinator, a social worker, a medical anthropologist, a health project planner, and volunteers.

The program's primary care provider assists in the development of the initial palliative care plan and maintains active involvement while the patient is enrolled in the project. For each patient, the project uses an interdisciplinary team composed of a health planner, a nurse, a doctor, and a volunteer coordinator. The volunteers care for patients and offer support to families. Volunteers are trained using the highly successful Volunteer Emergency Medical Service Program. Each volunteer also receives at least four hours training by the volunteer coordinator, using a culturally sensitive guide and materials developed specifically for this program. Community volunteers provide routine medical assistance in local communities between physician and nurse visits. Teen volunteers also spend time with some patients. The teens, trained using special materials developed by the project, receive school credit for their volunteer activities. Bristol Bay Area Health Corporation also is developing a curriculum and training program for all of its health care workers on death, dying, and hospice care.

These services allow patients and families to remain in comfortable and familiar settings. The program serves 15 to 20 patients per month; travel restricts the project's ability to care for many more patients. The program was implemented in 1999. The percentage of home deaths for selected causes has increased from 33 percent in 1997 to 77 percent in 2001. The program is seeking expansion throughout Alaska, to be centralized in Anchorage.

This Helping Hands Program has developed several exportable tools including training curricula for caregivers, volunteers, and community health aide/practitioners (CHA/P); brochures; pain assessment tools; and a patient journal. The project has also done significant work in focus groups in three culturally diverse villages, creatively adapting the focus group questions to this diverse audience.

Dialysis program with a bereavement component—

BAYSTATE MEDICAL CENTER, SPRINGFIELD, MA

Baystate Medical Center in Springfield, Massachusetts has implemented a noteworthy bereavement program—a memorial service for dialysis patients. Previously, staff and patients had to cope individually with “the disappeared,” those who one day did not appear for dialysis due to death and were never recognized by the staff or by fellow patients who sat side by side with them for hours during dialysis. Baystate changed this, with tributes at the time of death, as well as annual memorial services that allow families and clinicians together to honor the memory of loved ones.

VI. Conclusion

CALIFORNIA HOSPITALS HAVE BEEN AMONG THE NATION'S leaders in developing and implementing dedicated hospital-based palliative care services. Programs like California's own CHIPS and the national PCLC, that focus on palliative care service development and incorporate education and mentoring, have successfully helped these California hospitals establish their palliative care services. Initiatives in California by CHW, Kaiser, Sutter, and the VA demonstrate the power of system-wide programs in promoting development of palliative care services.

The success of CHIPS and PCLC, combined with data from the California surveys of 2000 and 2004, also reveal two disturbing trends. First is the low prevalence of palliative care services in county hospitals, revealing that many of California's most vulnerable residents have no access to palliative care. Second is that while new palliative care services are being initiated across the state, some existing services are closing down.

Given that 65 percent of CHIPS hospitals worked with other hospitals to develop palliative care services and that CHW, Kaiser, Sutter, and the VA all have system-wide initiatives to develop palliative care, the number of California hospitals with such services should have increased markedly between 2000 and 2004. Yet, in 2004, only 23 percent of the state's hospitals had palliative care services, an increase of merely 5 percentage points. This increase could be accounted for almost entirely by the new CHIPS programs. Yet there were certainly many non-CHIPS hospitals that started services, so these data suggest that while new programs were launching, others must have failed.

The clear implication of these figures is that hospitals need support not only to establish palliative care services but also to sustain them. A follow-on program, modeled on CHIPS or PCLC, which focuses on program sustainability, is in the planning stages. In this regard, it is also noteworthy that nine hospitals that participated in CHIPS returned to attend PCLC. This finding suggests that for some institutions, the process of establishing a palliative care service is iterative, and that ongoing support may be needed.

Appendix A: California Hospitals that Participated in CHIPS and/or PCLC

California Hospital Initiative in Palliative Services (CHIPS) Alumni

SITE	CITY
1 Alameda County Medical Center	Oakland
2 Cedars-Sinai Medical Center	Los Angeles
3 Children's Hospital Central California	Madera
4 Citrus Valley Medical Center, Inter-Community Campus	Covina
5 Community Hospital of the Monterey Peninsula	Monterey
6 Dominican Hospital	Santa Cruz
7 Enloe Medical Center	Chico
8 Henry Mayo Newhall Memorial Hospital	Valencia
9 Hoag Memorial Hospital Presbyterian	Newport Beach
10 John Muir Medical Center	Walnut Creek
11 Kaiser Foundation Hospital, Manteca	Manteca
12 Kaiser Permanente Oakland/Richmond Medical Center	Oakland
13 Kaiser Permanente Panorama City	Panorama City
14 Kaiser Permanente Sacramento/Roseville Medical Center	Sacramento
15 Kaiser Permanente San Francisco Medical Center	San Francisco
16 Kaweah Delta Health Care District	Visalia
17 Loma Linda University Medical Center	Loma Linda
18 Los Robles Hospital & Medical Center	Thousand Oaks
19 Mark Twain St. Joseph's Hospital	San Andreas
20 Mayers Memorial Hospital District	Fall River Mills
21 Mills-Peninsula Health Services	Burlingame
22 NorthBay Medical Center	Fairfield
23 Riverside Community Hospital	Riverside
24 Saint Agnes Medical Center	Fresno
25 Salinas Valley Memorial Healthcare System	Salinas
26 San Gabriel Valley Medical Center	San Gabriel
27 Santa Clara Valley Medical Center	San Jose
28 Santa Monica - UCLA Medical Center	Santa Monica
29 Santa Rosa Memorial Hospital	Santa Rosa
30 Scripps Mercy Hospital	San Diego
31 Sierra Nevada Memorial Hospital	Grass Valley
32 St. Joseph's Medical Center	Stockton
33 St. Luke's Hospital	San Francisco
34 St. Mary's Medical Center	San Francisco
35 Sutter Roseville Medical Center	Roseville
36 Torrance Memorial Medical Center	Torrance
37 University of California San Diego Healthcare	San Diego
38 USC/Norris Cancer Hospital	Los Angeles

California Alumni of the Palliative Care Leadership Center (PCLC) Program

SITE	CITY	SITE	CITY
1 Alta Bates Summit Medical Center	Berkeley	36 Providence St Joseph Medical Center	Burbank
2 Aptium Oncology	Los Angeles	37 Saddleback Memorial Medical Center	Laguna Hills
3 Bakersfield Memorial Hospital	Bakersfield	38 San Benito Healthcare District	Hollister
4 Barlow Respiratory Hospital	Los Angeles	39 San Francisco General Hospital	San Francisco
5 California Pacific Medical Center	San Francisco	40 San Francisco Veterans Affairs Medical Center	San Francisco
6 Cedars-Sinai Medical Center	Los Angeles	41 San Joaquin Community Hospital	Bakersfield
7 Children's Hospital Central California	Madera	42 Santa Clara Valley Medical Center	San Jose
8 Chinese Hospital	San Francisco	43 Scripps Mercy Hospital	San Diego
9 Cottage Health System	Santa Barbara	44 Sequoia Hospital	Redwood City
10 Eden Medical Center	Castro Valley	45 Seton Medical Center	Daly City
11 El Camino Hospital	Mountain View	46 Sharp Memorial Hospital	San Diego
12 Enloe Medical Center	Chico	47 Sherman Oaks Hospital	Sherman Oaks
13 Glendale Adventist Medical Center	Glendale	48 Snowline Hospice	Placerville
14 Hospice & Palliative Care of Contra Costa	Pleasant Hill	49 St. Helena Hospital	St. Helena
15 Hospice of the Valley	San Jose	50 St. John's Regional Medical Center	Oxnard
16 Hospice Touch	Santa Ana	51 St. Mary's Medical Center	San Francisco
17 John Muir Health	Walnut Creek	52 St. Vincent Medical Center	Los Angeles
18 Kaiser Foundation Hospital	Oakland	53 Tahoe Forest Hospital	Truckee
19 Kaiser Permanente Orange County	Anaheim	54 University of California, Davis Medical Center	Sacramento
20 Kaiser Permanente-Vallejo	Vallejo	55 University of California, San Diego Healthcare	San Diego
21 Kaiser Walnut Creek	Walnut Creek	56 ValleyCare Medical Center	Pleasanton
22 Kaweah Delta Health Care District	Visalia	57 Washington Hospital	Fremont
23 Loma Linda University Medical Center	Loma Linda		
24 Long Beach Memorial Medical Center	Long Beach		
25 Los Angeles County Medical Center	Los Angeles		
26 Marian Medical Center	Santa Maria		
27 Memorial Medical Center	Modesto		
28 MemorialCare Medical Centers	Long Beach		
29 Mercy Hospital	Bakersfield		
30 Mercy Medical Center, Mt. Shasta	Mt. Shasta		
31 Mercy San Juan Medical Center	Carmichael		
32 Miller Children's Hospital	Long Beach		
33 Motion Picture & Television Fund Hospital	Woodland Hills		
34 O'Connor Hospital	San Jose		
35 Presbyterian Intercommunity Hospital	Whittier		

Appendix B: Contact Information for Innovative Palliative Care Services

Baystate Medical Center, Springfield, MA

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Baystate Medical Center
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Fax: (413) 794-9803
Email: lewis.cohen@bhs.org

Carolina Healthcare System, Charlotte, NC

Judith Kinsella R.N., M.S.N., C.H.P.N.
Assistant Vice President of Medical Services
Hospice and Palliative Care Charlotte Region
Hospice at Charlotte/Hospice Lake Norman/
Hospice of Lincoln County/Kids Path/Palliative
Medicine Consultants
1420 East Seventh Street
Charlotte, NC 28204
Phone: (704) 335-3512
Fax: (704) 375-8620
Email: kinsellaj@hospiceatcharlotte.org
Web site: www.hpccr.org

Community Hospital of the Monterey Peninsula, Monterey, CA

Mary K. Brusuelas, R.N., B.S.N.
Program Manager, Palliative Medicine Consult Service
Email: mary.brusuelas@chomp.org

Froedtert Hospital, Medical College of Wisconsin, Milwaukee, WI

David Weissman, M.D.
Email: dweissma@mail.mcw.edu
Web site: www.palliativecareeducation.com

Helping Hands Program, Bristol Bay, AK

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Alaska Native Tribal Health Consortium
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Hoag Memorial Hospital Presbyterian, Newport Beach, CA

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Simultaneous Care Project, Central Valley, Sacramento, CA

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Thomas Palliative Care Services, Richmond, VA

Patrick Coyne, M.S.N., A.P.R.N., F.A.A.N.
Thomas Palliative Care Services at VCU Med Center
Email: user479069@aol.com

Massey Cancer Center
401 College Street
Richmond, VA 23298

Veterans Integrated Service Network (VISN) 3, NY/NJ

Carol Luhrs, M.D.
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Appendix C: Resources

The authors have found the following resources to be useful across the spectrum of information available for palliative care operational models, clinical services, and educational opportunities. This list is representative but by no means exhaustive, and the authors do not attest to the accuracy of all the information contained in each resource.

Advance Directives

California Coalition for Compassionate Care
www.finalchoices.calhealth.org/advance_health_care_directives.htm

California's Physician Continuing Education in Pain and End-of-Life Care Requirement (AB487)

California Business and Professions Code
www.leginfo.ca.gov/cgi-bin/displaycode?section=bpc&group=02001-03000&file=2190-2196.5

California Coalition for Compassionate Care
www.finalchoices.calhealth.org/C4_textfiles/ab_487_bill_20011005_chaptered.pdf

Designing Hospital-Based Palliative Care Services

Center to Advance Palliative Care (CAPC) www.capc.org/

End-of-Life Data Sets

Epidemiology of Dying and End-of-Life Experience
www.edeledata.org/search/home.html

Epidemiologic Data About Deaths / Death in California

Brown Atlas of Dying. "Facts on Dying: California State Profile," www.chcr.brown.edu/dying/caprofile.htm

Educational Resources

American Academy of Hospice and Palliative Medicine (AAHPM) www.aahpm.org
Resources: www.aahpm.org/resources/
UNIPAC Book Series: Hospice/Palliative Care Training for Physicians, A Self Study Program: www.association-office.com/aahpm/etools/products/index.cfm
Primer in Palliative Care: www.association-office.com/AAHPM/etools/products/products.cfm

Americans for Better Care of the Dying (ABCD)
"Clinicians—to Improve Daily Practice":
www.abcd-caring.org/tools/actionguides.htm#clinicians

Disseminating End-of-Life Education to Cancer Centers (DELEtCC) <http://deletcc.coh.org/>

Education in Palliative and End-of-Life Care (EPEC)
www.epec.net

End-of-Life Nursing Education Consortium (ELNEC)
Curriculum: www.aacn.nche.edu/el nec/curriculum.htm

End of Life/Palliative Education Resource Center (EPEC)
www.eperc.mcw.edu/
"Fast Facts": www.eperc.mcw.edu/ff_index.htm

National Internal Medicine Residency Curriculum Project
www.mcw.edu/pallmed/html/about1.html

Ian Anderson Continuing Education Program in End-of-Life Care www.cme.utoronto.ca/endoflife/

Expertise in Palliative Care

Chaplain Expertise

Association for Clinical Pastoral Education Inc. (ACPE)
www.acpe.edu/

Curricula/Competencies

AAHPM Core Curriculum www.aahpm.org/resources/

American Board of Hospice and Palliative Medicine (ABHPM) www.abhpm.org/

Department of Veterans Affairs Interprofessional Fellowship Program in Palliative Care
www.va.gov/oaa/fellowships/Palliative.asp

EPEC Faculty Development Conference www.epec.net

Harvard Medical School Center for Palliative Care Program in Palliative Care Education and Practice Faculty Development
www.hms.harvard.edu/cdi/pallcare/

Hospice and Palliative Nurses Association (HPNA)
www.hpna.org/

Open Society Institute and Soros Foundations Network Project on Death in America (PDIA) Faculty Scholars Program www.soros.org/death/fs_announcement.htm

PDIA Social Work Leadership Development Awards
www2.soros.org/death/socialrfa.htm

Stanford Faculty Development Center for Medical Teachers www.stanford.edu/group/SFDP/

Nurse Expertise

ELNEC www.aacn.nche.edu/ELNEC/

HPNA www.hpna.org/

National Board for Certification of Hospice and Palliative Nurses www.nbchpn.org/

Physician Expertise

ABHPM www.abhpm.org

EPEC Faculty Development Conference www.epec.net

Harvard Medical School Center for Palliative Care
Program in Palliative Care Education and Practice
Faculty Development Course
www.hms.harvard.edu/cdi/pallcare/

PDIA Faculty Scholars Program
www2.soros.org/death/faculty_scholars_program.htm

Stanford Faculty Development Center for Medical
Teachers www.stanford.edu/group/SFDP/

Social Work Expertise

PDIA Social Work Leadership Development Award
www.swlda.org/archive/

Smith College School for Social Work
www.smith.edu/ssw/geaa/academics_ccertificate.php

Guidelines

Published standards, guidelines, professional recommendations, position or consensus papers, principles of professional practice for palliative care include:

Agency for Health Care Policy and Research. “Cancer Pain Management Guidelines” (1994).

American Academy of Neurology. “Palliative Care in Neurology” (1996), www.aan.com/about/ethics/Palliative%20Care.pdf

American Academy of Pain Medicine. “Quality Care at the End of Life” (1998), www.painmed.org/product-pub/statements/pdfs/quality_care-end_of_life.pdf

American Geriatric Society. “The Care of Dying Patients” (1994; revised 2002), www.americangeriatrics.org/products/positionpapers/careofd.shtml

American Medical Association (AMA). Report from the Council on Scientific Affairs: “Good Care of the Dying Patient.” *Journal of the American Medical Association (JAMA)* 1996; 275:474–478.

AMA. “Optimal Use of Orders-Not-to-Intervene and Advance Directives,” www.ama-assn.org/ama/pub/category/8462.html

AMA Council on Ethical and Judicial Affairs. “Guidelines for Appropriate Use of Do-Not-Resuscitate Orders.” *JAMA* 1991; 265:1868–71.

American Nurses Association. “Pain Management and Control of Distressing Symptoms in Dying Patients” (1991; revised 2003), www.nursingworld.org/readroom/position/ethics/etpain.htm

American Pain Society. “Principles of Analgesic Use in the Treatment of Acute and Cancer Pain” (5th edition), www.ampainsoc.org/pub/principles.htm

American Society of Pain Management Nurses. Position statement: “Treatment of Pain at the End of Life” (1997; revised 2006), www.ampainsoc.org/advocacy/treatment.htm

American Thoracic Society. “Withholding and Withdrawing Life-Sustaining Therapy” (1991), www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=1892317
Society of Critical Care Medicine Ethics Task Force.

Cassel, C.K., and Foley, K.M. “Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine” (1999), Milbank Memorial Fund, www.milbank.org/endoflife/index.html

Cherny, N.I., Coyle, N., and Foley, K.M. “Guidelines in the care of the dying patient.” *Hematol Oncol Clin North Am* 1996;10: 261–86.

Consensus Report on the Ethics of Forgoing Life-Sustaining Treatments in the Critically Ill. *Critical Care Medicine* 1990;18:1435–1439

HPNA. “Statement on the Scope and Standards of Hospice and Palliative Nursing Practice” (2000), www.hpna.org/Publications_Home.aspx

Institute of Medicine. “Approaching Death: Improving Care at the End of Life” (1997), www.nap.edu/readingroom/books/approaching/

National Consensus Project for Quality Palliative Care. “Clinical Practice Guidelines for Quality Palliative Care,” www.nationalconsensusproject.org/

NHPCO and the National Hospice Work Group. “End Report on the Alpha and Beta Pilots of End Result Outcome Measures” (1998-2000), www.nhpc.org/files/public/OCFFINALRPT.pdf

NHPCO. “A Pathway for Patients & Families Facing Terminal Illness” (1997). www.nhpc.org/public/articles/FOR.pdf

Oncology Nursing Society and Association of Oncology Social Work. “Joint Position on End-of-Life Care” (1998; revised 2003), www.aosw.org/docs/pos-ons.pdf

Teno, J.M. et al. “Toolkit of Instruments to Measure End-of-Life Care (TIME),” www.chcr.brown.edu/pcoc/Advanc.htm

Weissman, D. *Improving End-of-Life Care: A Resource Guide for Physician Education*. Medical College of Wisconsin, 1998
www.mcw.edu/display/router.asp?DocID=196

World Health Organization. “Palliative Care,”
www.who.int/cancer/palliative/en/

Marketing Materials

CAPC www.capc.org/building-a-hospital-based-palliative-care-program/implementation/marketing

Medicare Fee-for-Service Policies

Centers for Medicare and Medicaid Services
www.cms.hhs.gov/home/medicare.asp

Norms / Standards of Practice, Accreditation

California Hospice & Palliative Care Association
(CHAPCA) www.calhospice.org

Canadian Hospice Palliative Care Association (CHPCA)
www.chpca.net/home.htm
Norms of Practice:
www.chpca.net/initiatives/norms-general.htm

Joint Commission www.jointcommission.org

National Hospice and Palliative Care Organization
(NHPCO) www.nhpco.org
Hospice Standards of Practice:
This material is no longer available to view online,
but you may purchase it at:
[http://iweb.nhpco.org/iweb/Purchase/
ProductDetail.aspx?Product_code=711077](http://iweb.nhpco.org/iweb/Purchase/ProductDetail.aspx?Product_code=711077)

State of Palliative Care Research

National Institutes of Health State-of-the-
Science Conference. “Statement on Improving
End-of-Life Care,” [http://consensus.nih.gov/2004/
2004EndOfLifeCareSOS024html.htm](http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm)

Crosswalk of JCAHO Standards and Palliative Care,
CAPC www.capc.org/jcaho-crosswalk

National Quality Forum www.qualityforum.org

University HealthSystem Consortium. Palliative Care
Benchmarking Project (2004), www.uhc.edu/

U.S. News and World Report. “Best Hospitals 2006,”
[www.usnews.com/usnews/health/best-hospitals/
tophosp.htm](http://www.usnews.com/usnews/health/best-hospitals/tophosp.htm)

Tools for Analyzing Financial Outcomes and Developing a Business Case

CAPC www.capc.org/

Utilization of Acute Care Services in California

Office of Statewide Health Planning and Development
www.oshpd.cahwnet.gov/

Appendix D: Endnotes

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