



CALIFORNIA  
HEALTHCARE  
FOUNDATION



COALITION FOR  
COMPASSIONATE CARE  
OF CALIFORNIA



# Dying in California: A Status Report on End-of-Life Care

OCTOBER 2015

# Contents

## About the Authors

Kelley Queale is a program director for the Coalition for Compassionate Care of California, a statewide collaborative dedicated to the advancement of palliative medicine and end-of-life care in California.

Kate Meyers, MPP, is a health care consultant who focuses on improving organizations' capacity to deliver high-quality care that is aligned with patient preferences and values.

## About the Coalition

The Coalition for Compassionate Care of California (CCCC) is a coalition of organizations, institutions, health care providers, state agencies, and individuals working together to increase access to high-quality, compassionate palliative and end-of-life care for all people. Through advocacy, education, and resource development, CCCC works to ensure that organizations and communities have the information, knowledge, and tools to expand access to quality care in the face of serious illness.

For more information, visit [www.coalitionccc.org](http://www.coalitionccc.org).

## About the Foundation

The California HealthCare Foundation (CHCF) is leading the way to better health care for all Californians, particularly those whose needs are not well served by the status quo. We work to ensure that people have access to the care they need, when they need it, at a price they can afford.

CHCF informs policymakers and industry leaders, invests in ideas and innovations, and connects with changemakers to create a more responsive, patient-centered health care system.

For more information, visit [www.chcf.org](http://www.chcf.org).

©2015 California HealthCare Foundation

## 3 Delivery of Care

Progress

Gaps and Opportunities

## 7 Clinician-Patient Communication and Advance Care Planning

Progress

Gaps and Opportunities

## 8 Professional Education and Development

Progress

Gaps and Opportunities

## 11 Policies and Payment Systems

Progress

Gaps and Opportunities

## 13 Public Education and Engagement

Progress

Gaps and Opportunities

## 15 Looking Ahead

## 16 Appendix

## 19 Endnotes

## Delivery of Care

In its 2014 consensus report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*,<sup>1</sup> the Institute of Medicine (IOM)<sup>2</sup> set out five core recommendation areas fundamental to improvement in end-of-life care in the US: (1) delivery of care, (2) clinician-patient communication and advance care planning, (3) professional education and development, (4) policies and payment systems, and (5) public education and engagement.

In California, improving end-of-life care has been a strong focus of providers, insurers, legislators, and advocates for the last decade. This report is a snapshot of the state's progress in terms of the IOM's recommendations. The information is based on research and informal conversations with leaders in the field, as well as an online survey with several experts in palliative care and advance care planning around the state.

Overall, California has made significant strides in creating a supportive framework for end-of-life care. A wide variety of stakeholders — including palliative care leaders, health insurers, delivery systems, skilled nursing facilities, hospices, clinics, physician champions, nurses, religious leaders, and advocacy groups — have come together to support policy reform, outreach, and education. State government also has brought together key players to develop new programs and policies that support palliative care.

However, significant challenges remain. The growing demand for palliative care far outpaces the capacity of services in California. In particular, palliative care specialists are in short supply, and certification programs are limited. Reliable funding streams do not yet exist. While knowledge is growing about best practices and quality standards, they have not yet been broadly implemented.

Following are summaries of the state's current progress in each of the IOM report's five recommendation areas.

**IOM RECOMMENDATION 1.** Government health insurers and care delivery programs, as well as private health insurers, should cover the provision of comprehensive care for individuals with advanced serious illness who are nearing the end of life. Comprehensive care should:

- ▶ Be seamless, high-quality, integrated, patient-centered, family-oriented, and consistently accessible around the clock
- ▶ Consider physical, emotional, social, and spiritual needs of patients and families/caregivers
- ▶ Be competently delivered by professionals with appropriate expertise and training
- ▶ Include coordinated, efficient, and interoperable information transfer across all providers and settings
- ▶ Be consistent with individuals' values, goals, and informed preferences

People with serious advanced illness and their families could benefit from all clinicians having a basic level of competence in addressing palliative care needs; some patients may also require the involvement of interdisciplinary teams of professionals specifically trained in palliative care. However, specialty palliative care is currently unavailable in many geographic areas and in many care settings.

### Progress

California has made substantial progress in increasing access to specialty palliative care services, both at the state policy level and at the delivery system level. A variety of organizations and entities across the state have been laying the groundwork.

#### **Knowledge base about palliative care in California.**

Several organizations and individuals have published information and data about palliative care in California, including program characteristics, promising practices, and capacity compared to need. (See Appendix, Table 1.) This comprehensive knowledge base about California practices and gaps is a valuable resource for program development and improvement.

**State legislation, regulation, and demonstration programs.** The California legislature and Department of Health Care Services have enacted policies and pilot programs that support palliative care services. (See Appendix, Table 2.) Senate Bill (SB) 1004 requires Medi-Cal (Medicaid) managed care plans to ensure the delivery of palliative care services to beneficiaries. Several of the experts surveyed for this report asserted that SB 1004 — if implemented with clear expectations and adequate technical assistance to plans — presents an extremely powerful opportunity for growth of palliative care in the state.

**Cross-sector commitment.** The Berkeley Forum<sup>3</sup> brought together leaders of major health insurers, delivery systems, state government, and health policy experts from the University of California, Berkeley, to collaborate on ways to increase choice and value for patients nearing the end of life. The Forum's 2014 report, *Honoring Patients' Wishes: Expanding Palliative Care in California*, describes the potential impact and challenges of expanding access to community-based palliative care, recommended priority areas, and promising models for care outside the hospital.<sup>4</sup>

**Health care delivery organizations.** The IOM report specifies that health care delivery organizations should provide all people with advanced serious illness access to skilled palliative care or hospice care in all settings; that palliative care should include access to an interdisciplinary palliative care team; and that care should include public reporting of aggregate quality and cost measures for all aspects of the health care system related to end-of-life care. While far from meeting these standards, California's health care organizations have made progress. Notable examples include the following:

- ▶ **Major health care systems.** Some of California's largest health care systems have implemented palliative care services across multiple care settings (see box). This work has helped inform the field about care models and the impact of palliative care services on care quality, satisfaction, and costs.
- ▶ **Initiatives supporting palliative care.** The California HealthCare Foundation (CHCF) supports initiatives to strengthen inpatient and outpatient palliative care services across the state. The Spreading Palliative Care in Public Hospitals initiative (2008-13) supported implementation of inpatient palliative care in all 17 of California's public hospitals (including 13 new

### Three Large System Examples

**Kaiser Permanente**, the integrated health plan/provider group model, provides services under global budgets rather than fee for service. Both its Northern and Southern California regions are working on expanding clinic-based and home-based palliative care models, as well as an evidence-based advance care planning program.

**Sharp HealthCare** serves a large risk-sharing population through its accountable care organization. Its Transitions Program provides home-based and telephonic palliative care services concurrent with disease-directed treatment as desired by the patient. The program focuses on in-home consultation, evidence-based prognostication of disease course, caregiver support, and advance care planning.\*

**Sutter Health** has an Advanced Illness Management (AIM) program in which teams of nurses and care managers provide clinical care and care management at home, in the clinic, in the hospital, and by phone. The focus is on patient/caregiver engagement, goal-setting, and self-management.† Sutter is also developing an integrated palliative care service with primary palliative care provided by primary care physicians who will receive education in end-of-life care, communication, and pain and symptom management. Secondary palliative care will be provided by specialists.‡

Note: Both Kaiser Permanente and Sutter Health were mentioned in the *Dying in America* report.

\*D. R. Hoefler, S. K. Johnson, and M. Bender, "Development and Preliminary Evaluation of an Innovative Advanced Chronic Disease Care Model," *Journal of Clinical Outcomes Management* 20, no. 9 (2013).

†M. C. Labson et al., "Innovative Models of Home-Based Palliative Care," *Cleveland Clinic Journal of Medicine* 80 (e-Suppl 1) (2013): e-S30.

‡Survey response from Jim McGregor, AIM medical director, Sutter Care at Home, July 6, 2015.

programs).<sup>5</sup> CHCF is now working with the same hospitals to start or strengthen community-based palliative care services (CBPC) at their institutions. The Palliative Care Action Community (2013-14) supported networking and collaborative learning among 21 provider organizations focused on strengthening or expanding their CBPC services in clinics and in homes.<sup>6</sup> Looking ahead, organizations developing community-based services can receive mentoring and support from the Palliative Care Leadership Center at the University of California, San Francisco (UCSF), as it expands its focus to include outpatient services.

- ▶ **Skilled nursing facilities.** Increasing the capacity of California's nursing homes to provide compassionate, quality end-of-life care was the goal of the CARE (Compassion And Respect toward the End of life) task force, which brought together industry leaders representing statewide coalitions, trade associations, advocates, regulators, and providers. The resulting CARE Recommendations, first published in 2010 and re-issued in 2015, provide practical concepts, tools, and resources to guide nursing homes in implementing palliative care.
- ▶ **Geography-based coalitions.** San Francisco's Department of Public Health and Department of Aging and Adult Services convened a diverse Palliative Care Task Force in 2014 to develop strategic recommendations focused on quality, finance, systems, and community engagement.<sup>7</sup> In an important and novel initiative, nine Southern California public and private health systems that serve more than 5 million people came together in 2014 to issue joint recommendations for improving care for people with advanced illness, with a focus on advance planning around end-of-life needs.<sup>8</sup>
- ▶ **Insurers and payers.** Payers increasingly recognize the importance of palliative care services. Medi-Cal plans will ensure the delivery of palliative care services to beneficiaries, as required by SB 1004. Both public and private health plans will be able to learn from the implementation process.

Various payers are planning and testing models for delivering palliative care in partnership with providers. CHCF's Payer/Provider Partnerships initiative supported 10 payer/provider duos (or trios) in a six-month collaborative planning process in 2014-15 to design an approach

for providing and paying for community-based palliative care. Most of these pairs are expected to continue receiving support during 2015-17 as they further implement their plans, test their payment models, and evaluate the impact of their services.<sup>9</sup>

The following examples illustrate how two commercial payers are approaching palliative care:

- ▶ **Health Net** is participating in the Payer/Provider Partnerships initiative with three different provider organizations in two geographic areas. The San Diego area participants are LightBridge Hospice & Palliative Care and Rady Children's Hospital. In Orange County, the provider organization is CareChoices Hospice and Palliative Services. These partners have begun their pilot implementation of services provided to defined populations in shared-risk plans with payment from Health Net. Based on the results of these pilots (as well as experience from another pilot in Arizona), Health Net hopes to refine and strengthen its approach to partnering with provider organizations to increase access to community-based palliative care.<sup>10</sup>
- ▶ **Anthem** is also participating in the Payer/Provider Partnerships initiative and will be piloting the provision of CBPC services in collaboration with the UCLA Medical Center. Anthem has had an extended hospice benefit in place since January 2014, in which its fully insured group members across California are eligible for the hospice benefit when their life expectancy is 12 months or less, rather than Medicare's restriction of six months or less. Anthem has also integrated palliative and end-of-life care as about half of the content within its internal Oncology Certification online training for nurses and case managers. Recently, Anthem established a new Palliative Care Strategy Team for the entire organization; it includes medical directors from various lines of business, payment and reimbursement experts, and palliative care experts.<sup>11</sup>

## Gaps and Opportunities

While health care providers and insurers are making progress, large gaps in access remain. A 2014 study sponsored by CHCF examined the estimated need for palliative care among individuals in the last year of life — compared to the availability of hospital and community programs in California.<sup>12</sup> This analysis found that

program capacity falls far short of need. The 189 community-based palliative care programs identified are estimated to have capacity to serve 24%-37% of those needing palliative care in the last year of life; and 186 inpatient programs are estimated to have capacity to serve 33%-50% of those in need. Not only is the statewide supply insufficient, but many counties lack specialty palliative care entirely. Importantly, no CBPC programs were identified in 22 counties, and no inpatient services were found in 19 counties.

Experts surveyed as part of this report cited a number of potential approaches to advancing access to comprehensive palliative care services.

**Payment.** While some health plans are testing approaches to paying provider organizations to deliver specialty palliative care services, continued innovation in payment models and improved definitions of eligibility standards and covered services are needed. Careful consideration should be given to how payment can better value high-quality care. Some survey respondents felt payment should not just create incentives for processes to take place (such as completion of an advance directive) but should consider how to recognize and pay for the time necessary to improve care quality and outcomes. Others felt that process metrics such as completion of advance directives could be useful levers for change, because even basic pay for performance metrics would motivate organizations to identify workflows to get it done.

**Policy.** In addition to citing the potential of SB 1004 to expand access to palliative care for Medi-Cal beneficiaries, survey respondents spoke of the need for policy changes to support integration of financing for social services and medical care. Rather than today's model of distinct silos for various aspects of social services (such as in-home support, transportation, and food services) and medical care, integrated or aligned financing approaches could better support people with advanced illness and help keep them in their homes longer if that is their preference. Others recommend consideration of a concurrent care policy (disease-directed care alongside palliative care) similar to the Partners for Children pediatric palliative care program.<sup>13</sup>

A policy challenge is California's Corporate Practice of Medicine Law, which prohibits corporations from employing physicians to provide medical services, with limited

exceptions.<sup>14</sup> The law restricts hospices from employing physicians to provide care across the continuum — from inpatient, to outpatient, to hospice care. One respondent noted that an exemption for hospice and palliative medicine physicians would support smoother transitions between care settings if the same physician could care for the patient over time and place.

California Health and Human Services Agency Secretary Diana Dooley noted her own commitment and that of the state to quality end-of-life care. "Making personal choices about the medical care we want at the end of our lives is very important to me," she said, noting that "thoughtful, compassionate end-of-life care is one of the key goals of Let's Get Healthy California, our statewide effort to make California the healthiest state in the nation by 2022."

**Quality standards and reporting.** Much remains to be done to reach the IOM report's goal that "care should include public reporting of aggregate quality and cost measures for all aspects of the health care system related to end-of-life care." While guidelines and standards for high-quality palliative care have been established by clinical experts, specialty care associations, and quality leaders,<sup>15</sup> these standards are not yet consistently embedded in and monitored by palliative care programs in California. Some survey respondents noted a lack of quality measures and standardization regarding expected services and staffing among California's growing number of palliative care programs. Some noted that quality and performance metrics are essential, including patient-centered quality measures on issues such as functional status, cognitive decline after hospitalization, and caregiver burden. Regarding standards for staffing palliative care services, a respondent noted that "one is not better than none" — meaning that establishing palliative care programs with just one provider or one discipline rather than an interdisciplinary team might erode impact and quality.

**Workforce.** The supply of specialty palliative care providers is insufficient to meet the needs of all people with serious advanced illness and their families, and basic palliative care knowledge is lacking among providers who care for this population. The respondents said that continued investment in workforce development and training, both at the specialty and generalist / primary palliative care level, is essential.

# Clinician-Patient Communication and Advance Care Planning

**IOM RECOMMENDATION 2.** Professional societies and other organizations that establish quality standards should develop standards for clinician-patient communication and advance care planning that are measurable, actionable, and evidence based. These standards should change as needed to reflect the evolving population and health system needs and be consistent with emerging evidence, methods, and technologies. Payers and health care delivery organizations should adopt these standards and their supporting processes, and integrate them into assessments, care plans, and the reporting of health care quality. Payers should tie such standards to reimbursement, and professional societies should adopt policies that facilitate tying the standards to reimbursement, licensing, and credentialing to encourage:

- ▶ All individuals, including children with the capacity to do so, to have the opportunity to participate actively in their health care decision-making throughout their lives and as they approach death, and receive medical and related social services consistent with their values, goals, and informed preferences
- ▶ Clinicians to initiate high-quality conversations about advance care planning, integrate the results of these conversations into the ongoing care plans of patients, and communicate with other clinicians as requested by the patient
- ▶ Clinicians to continue to revisit advance care planning discussions with their patients because individuals' preferences and circumstances change over time.

The quality of communication between clinicians and patients with advanced illness often falls far short of the ideal, particularly with respect to discussing prognosis, dealing with emotional and spiritual concerns, and finding the right balance between hoping for the best and preparing for the worst.

*“The best experiences occur when there are reliable systems for eliciting, recording, and using information about patients’ preferences; when clinicians are trained to carry out these tasks effectively and are properly compensated for doing so; and when patients’ wishes are known and respected to the extent possible.”*

— IOM *Dying in America* consensus report

Although clinicians have access to numerous resources on how to facilitate difficult conversations, actual training to develop the necessary communication skills is lacking from most standard medical curricula. Consequently, many clinicians struggle with advance care planning and end-of-life care discussions, and shy away from delivering bad news or having conversations with patients near the end of life.

## Progress

At the national level, some guidance and standards related to advance care planning, clinician-patient communication, and documentation of preferences for treatment are provided by a number of organizations, including the National Quality Forum,<sup>16</sup> the American Society for Clinical Oncology Institute for Quality,<sup>17</sup> the National Consensus Project on Quality Palliative Care,<sup>18</sup> the American Academy of Hospice and Palliative Medicine, and the Hospice and Palliative Nurses Association.<sup>19</sup>

The American Medical Association offers support and guidance for advance care planning within their Code of Medical Ethics.<sup>20</sup> The National POLST (Physician Orders for Life-Sustaining Treatment) Paradigm articulates a defined approach and standard components for POLST forms (developed at the state level) for eliciting and capturing end-of-life preferences. In California, the POLST form itself (and related trainings) provide a standard for documenting patient preferences. Questions on POLST usage and content that are part of California’s nursing home Minimum Data Set (MDS) in Section S support benchmarking and development of appropriate outcome measures for POLST.

A variety of health providers across California, such as Sharp HealthCare and Kaiser Permanente, are developing system-specific standards and processes for advance care planning. UCLA Health's Advance Care Planning and Services Initiative (ACPSI) is a systemwide effort to improve the quality of advance care planning for all patients, including those with serious illness. Contra Costa Regional Medical Center is participating in the Conversation Project's efforts to engage health systems in advance care planning initiatives.<sup>21</sup>

## Gaps and Opportunities

Establishing consistent, measurable communication standards and tying those standards to reimbursement are still areas needing improvement in California. Aside from the examples noted above, the standards that do exist are not routinely adopted by payers and providers.

Much of the work on advance care planning and clinician-patient communication in the state has focused on training. While California physicians and nurses often graduate with little formal training in communication skills — particularly communication focused on advance care planning and palliative care — there are a growing number of opportunities for post-graduate training offered throughout the state (see Recommendation 3).

California — as the only state to develop a standardized POLST curriculum and with a variety of experts and organizations already working together on these issues — is well positioned to develop and implement a robust system of quality standards, incentives, and support for conducting thoughtful conversations across public and private payers and providers, perhaps through a state-wide consensus-based process.

Despite the widespread use of POLST in California, a key challenge is the fact that, as a paper document that travels with the patient, the form can be easily lost. New legislation, Senate Bill (SB) 19, authorizes a pilot project to establish a registry of POLST forms. The pilot, to be coordinated by the Emergency Medical Services Authority, would inform the operation of a permanent, statewide POLST eRegistry. SB 19 requires that non-state funds be used for the development of the pilot, as well as any related startup costs and evaluation.

Related new legislation is Assembly Bill (AB) 637, authorizing nurse practitioners and physician assistants, under

the direction of a physician and within their scope of practice, to sign POLST forms and make them actionable medical orders. The bill goes into effect on Jan. 1, 2016. After collaborating with palliative care specialists and geriatricians, the California Medical Association co-sponsored this bill citing the importance of POLST as a tool for honoring end-of-life care preferences and that the bill could result in increased availability of POLST orders. Sixteen other states allow nurse practitioners and physician assistants to sign POLST forms.

## Professional Education and Development

**IOM RECOMMENDATION 3.** Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness who are nearing the end of life.

## Progress

The education of health professionals who provide care to people nearing the end of life has been strengthened by the establishment of the specialty of hospice and palliative medicine, along with palliative care specialties in nursing and social work. California's progress in professional education and development in palliative care is strongest for palliative care specialists, although efforts to build the skills of generalists are growing.

The following state-based organizations are helping expand education and training for palliative care specialists and generalists:

- ▶ **The California State University (CSU) Institute for Palliative Care** provides instructor-led and self-paced online professional development programs in palliative care for current and future nurses, social workers, chaplains, and allied health professionals. It also offers inter-professional courses for palliative care



teams. Over the two years the program has been offered, the institute has trained more than 1,100 health professionals all over the world (half from California) and expects continued growth online and at additional CSU campuses.

[csupalliativecare.org](http://csupalliativecare.org)

- ▶ **The Coalition for Compassionate Care of California (CCCC)** provides educational programs and supportive tools on advance care planning and palliative care. Their implementation of POLST includes (1) a comprehensive train-the-trainer program that has educated close to 1,000 health care professionals and (2) support of local POLST / advance care planning coalitions throughout the state that offer training for medical professionals. CCCC hosts professional development webinars and workshops on a broad range of topics related to palliative and end-of-life care, and tools and resources for medical professionals and patients/families.

[coalitionccc.org](http://coalitionccc.org) and [capolst.org](http://capolst.org)

- ▶ **UCSF's Palliative Care Leadership Center**, one of seven such centers across the country (and the only one west of Minneapolis), is sponsored by the Center to Advance Palliative Care (CAPC). It provides intensive two-day trainings and year-long mentoring to help health care teams start, sustain, and grow inpatient palliative care programs.

[www.capc.org](http://www.capc.org)

- ▶ **City of Hope, in partnership with the American Association of Colleges of Nursing**, has been providing palliative care training and train-the-trainer programs to nurses around the country for the past 15 years through ELNEC, the End-of-Life Nursing Education Consortium. Approximately 3,500 California-based trainers have gone through the program. It includes a core curriculum, as well as curricula specifically focused on critical care, geriatrics, pediatrics, public hospitals, and veterans.

[www.aacn.nche.edu](http://www.aacn.nche.edu)

- ▶ **City of Hope's Palliative Care Communication Institute** launched COMFORT Communication for Palliative Care Teams in 2015. This is a training curriculum designed for inter-professional, hospital-based palliative care teams. Future courses will include online training and communication training for oncology nurses.

[pccinstitute.com](http://pccinstitute.com)

- ▶ **Stanford Medical School's Palliative Care Training Portal** offers free online clinical training modules for doctors, nurses, psychologists, social workers, and other allied health personnel on a variety of clinical topics.

[palliative.stanford.edu](http://palliative.stanford.edu)

Additional innovative approaches sponsored by California's educational institutions include:

- ▶ **IMPACT-ICU** is an education and quality improvement program developed by UCSF and implemented at all University of California medical centers. It aims to improve integration of palliative care into intensive care units by training and supporting ICU nurses in patient symptom management, family support, and multidisciplinary communication about prognosis and goals of care.<sup>22</sup>

- ▶ **eDoctoring** is an online platform developed through a collaboration of the five University of California campuses. It supports training of medical students, residents, and practicing physicians using case studies and tutorials. The program includes a section on palliative and end-of-life care featuring content on pain management, improving communication with patients and family members, and ethical issues.<sup>23</sup>

Population-specific training programs include:

- ▶ **The Chinese American Coalition for Compassionate Care** offers a 30-hour training for Chinese-speaking hospice and palliative care volunteers.<sup>24</sup>
- ▶ **The Health Care Interpreter Network** collaborated with CHCF to develop a free curriculum for trainers of medical interpreters to use in preparing experienced interpreters to work in palliative care settings.<sup>25</sup>

- ▶ **The Children's Hospice and Palliative Care Coalition**, together with CCCC, developed a curriculum that teaches clinicians how to talk with parents about POLST.

[www.chpcc.org](http://www.chpcc.org)

- ▶ **Stanford University's Internet-based Successful Aging program (iSAGE)** offers training in the principles of successful aging and end of life for the general public as well as health workers, with specialized information on 13 ethno-cultural groups.<sup>26</sup>

[aging.stanford.edu](http://aging.stanford.edu)

National and state-based specialty associations, such as the American Academy of Hospice and Palliative Medicine, the National Hospice and Palliative Care Organization, the Hospice and Palliative Nurses Association, and the California Hospice and Palliative Care Association, offer a variety of educational opportunities for palliative care specialists. In addition, some health plans and medical groups across the state have or are developing in-house training programs for their providers and staff related to topics such as advance care planning.

Primary palliative care — particularly in California’s community health centers — is the focus of a comprehensive guidebook from CHCF titled *Weaving Palliative Care into Primary Care: A Guide for Community Health Centers*. It outlines strategic planning steps and education and training resources for clinics.<sup>27</sup>

## Gaps and Opportunities

Gaps persist in basic or primary palliative care education for generalists, both in medical and nursing school curricula and in continuing education. In addition, educational silos impede the development of inter-professional teams, which are integral to palliative care. The majority of clinicians in the state currently do not receive training in palliative care. Table 1 shows the size of the specialty

palliative care workforce in California, comparing 2012 to 2015. Despite a clear need for expansion in the palliative care workforce, growth has been stagnant over the past three years.

To broaden the field of trained professionals, the IOM report recommends that professional societies, accrediting organizations, and certifying boards all integrate palliative care training into their programs and requirements. While most of that work is national in scope, both licensure requirements for palliative care education and training for health care professionals can be state-based. California has a one-time requirement for most physicians to complete 12 hours of continuing medical education (CME) on pain management and the appropriate care and treatment of the terminally ill. There is also a requirement for CME on geriatric medicine for internists and family physicians whose practice comprises 25% or more patients over 65.<sup>28</sup>

The IOM report also recommends that health care delivery organizations, academic medical centers, and teaching hospitals should increase the number of available training positions for specialty-level palliative care. The number of Accreditation Council for Graduate Medical Education-approved positions for California has increased significantly over the past few years — from 22 positions in 2013/14 to 45 in 2015/16. While the number

**Table 1. California Palliative Care Workforce, by Discipline**

	IN CALIFORNIA	IN PALLIATIVE CARE	CERTIFIED/DESIGNATED	
	2012	2012	2012	2015
<b>Physicians</b>	100,544	No reliable data	914	903*
<b>Nurse Practitioners</b>	18,000	No reliable data	89	94†
<b>Nurses</b>	262,658	3,861	975 (25%)	941†
<b>Certified Nursing Assistants</b>	166,122	1,899	146 (8%)	122†
<b>Social Workers</b>	47,639	993	43 (4%)	71†
<b>Chaplains</b>	No reliable data	456	171 (38%)	327§

\*American Board of Medical Specialties

†Hospice and Palliative Nurses Association

‡National Association of Social Workers

§Association of Professional Chaplains (202) and the National Association of Catholic Chaplains (125)

Source: California State University Institute for Palliative Care, 2012.

of positions that programs have permission from their primary institution to fill is lower than these figures, this increase does signal growing interest from California institutions to train specialty palliative medicine providers.<sup>29</sup>

Experts surveyed for this report cited a number of potential approaches to moving California closer to achieving the recommendations on professional education and development: Regulatory and accrediting bodies could bolster palliative care education by identifying educational standards and endorsing programs, mandating CME in palliative care, and implementing standards for medical, nursing, and social work education to include didactic and experiential training in advance care planning conversations. Others felt that efforts should not focus on involving state regulatory agencies, as increased regulations can be inefficient or have unintended consequences. Some cited the need for expanded access to high-quality educational opportunities, including funding for providers to attend trainings, and expansion of training programs, including a mid-career palliative medicine fellowship. Others noted the potential of health care organizations to pay for palliative care certification or to reward certification with pay increases.

## Policies and Payment Systems

**IOM RECOMMENDATION 4.** Public and private insurance and health care delivery organizations should integrate the financing of medical and social services to support quality care aligned with patients' goals. If legislation is necessary, it should be pursued. The federal government should require public reporting on quality of care in the last year of life for programs it funds or administers, and should encourage all other payers and health care delivery systems to do the same. Interoperable electronic health records that incorporate advance care planning across time, settings, and providers should be used. States should be encouraged to develop and implement a POLST paradigm program.

In California, and in the US as a whole, the health care system is poorly designed to meet the needs of people near the end of life. Traditional financial incentives encourage providers to deliver more medical services even if they aren't beneficial, while many of the practical social services that might allow people to remain at home as long as desired — such as caregiver support, meal services, and family respite — are not arranged or funded by the same entities that pay for medical care. Integrated funding streams for medical and social services could help reduce fragmentation in patient care, improve quality of life for patients and families, and make more efficient use of resources by supporting patients to remain at home.

### Progress

**Integration of Financing of Medical and Social Services.** This recommendation has been described as “game-changing” by Diane E. Meier, MD, FACP, director of the Center to Advance Palliative Care (CAPC) and a member of the committee that developed the IOM report.<sup>30</sup> There is growing interest in integration of funding for medical and social services, and some states are piloting approaches to doing so in particular geographic regions or for specific populations.<sup>31</sup>

While the federal government would need to lead changes related to fee-for-service Medicare, California is well positioned to pursue greater integration of medical and social services because of the prevalence of managed care organizations and accountable care organizations (ACOs) in the state. These models offer greater flexibility in how their funds are used with global budget / capitated payment — including the ability to direct funds to social services and supports.<sup>32</sup> A 2014 analysis identified 58 ACOs in California,<sup>33</sup> representing 4%-6% of covered lives in the state.<sup>34</sup> Meier anticipates that “as our payment system moves from the fee-for-service, pay-for-volume system of the past toward versions of global budgeting, bundling, and capitation where providers accept financial risk and become more focused on quality than quantity, recognition of the inextricable association of social determinants with health care utilization is leading to change.”<sup>35</sup>

A pioneering model of integration of medical and supportive services is the California-born Program of All-inclusive Care for the Elderly (PACE). This program is aimed at enabling seniors who are eligible for nursing home care to remain in their communities. Services

include medical care (including specialty care and prescription drugs), adult day care, personal care, social services, respite care for caregivers, and hospital and nursing home care when necessary.<sup>36</sup> The six PACE sites in California can serve as models for medical/social service integration.

Several other California organizations are testing interventions to address high-intensity medical, social, and care coordination needs through Health Care Innovation Awards from the Centers for Medicare & Medicaid Innovation. Examples with potential lessons for medical/social services integration include:<sup>37</sup>

- ▶ **California Long-Term Care Education Center**, which is partnering with labor organizations, payers, provider organizations, and others to pilot the integration of In-Home Supportive Services (IHSS) providers into the health care system. IHSS funds personal home care aides; all recipients are disabled, and 85% are Medicare-Medicaid enrollees. The pilot is training IHSS personal home care aides in core competencies that will enable them to better support their IHSS consumer in interactions with the health care system and help reduce ED visits, hospital stays, and nursing home stays.
- ▶ **LifeLong Medical Care**, a multisite community health center, is partnering with the Center for Independent Living, which provides resources, education, and support to help people with disabilities to live independently. The initiative supports interdisciplinary team care for adults with disabilities who are at high risk of poor health outcomes and avoidable utilization of ED and inpatient care.
- ▶ **Rutgers University Center for State Health Policy** received an Innovation Award for an initiative in which California is a participant. Within this program, safety-net provider organizations in San Diego will use integrated care management teams (including nurses, social workers, and community health workers) to support clients' health care needs; at the same time, they will address the underlying determinants of health such as identifying stable housing, applying for health coverage or disability benefits, and facilitating transportation arrangements.

**Public Reporting of Quality in End-of-Life Care.** The IOM report calls for the federal government to require

public reporting on quality of care in the last year of life for programs it funds or administers, and to encourage all other payers and health care delivery systems to do the same. While this is beyond the scope of state-level action, California's experience with quality measurement and reporting in palliative care through the following initiatives can inform these efforts at both the state and national levels:

- ▶ **Palliative Care Quality Network (PCQN)** was established in 2009 at UCSF as a learning collaborative of palliative care providers focused on quality measurement and improvement. It uses shared data collection and analytic strategies to drive quality improvement initiatives and identify and disseminate best practices. Members include 31 hospital and health systems, predominantly from California.<sup>38</sup>
- ▶ **Palliative Care Research Cooperative Group (PCRC)** was established in 2010 to develop scientifically based methods that lead to meaningful evidence for improving quality of life for patients with advanced and/or potentially life-limiting illnesses, and their caregivers. UCSF is one of the coordinating centers of PCRC, and is a participant in a clinical trial testing the feasibility of a new quality-monitoring tool. City of Hope is another member site.<sup>39</sup>

**State POLST Program.** The recommendation also calls for states to develop and implement a POLST Paradigm program, and California has made significant progress in the five years since POLST legislation went into effect in the state in 2009. California established 27 community-based POLST coalitions, developed a two-day curriculum on the POLST conversation, built a statewide taskforce of stakeholders, launched a website to support POLST implementation, and developed educational materials in a range of languages.<sup>40</sup> (POLST is also discussed under Recommendations 3 and 5.)

## Gaps and Opportunities

Movement toward integration at the state level will require collaboration and blended or "braided" financing between a variety of federal and state government agencies, as well as private insurers and medical and social service providers. This is an area with significant opportunity and need for pilot testing and building new models.

Also needed is the development of interoperable electronic health records (EHRs) that incorporate advance care planning across time, settings, and providers. While large integrated systems like Kaiser Permanente and Sutter Health are progressing toward such well-developed EHR programs, most non-integrated systems and smaller providers, such as community health centers and skilled nursing facilities, lack interoperable systems. The implementation of EHRs that seamlessly share information across institutions and provider types is still a distant goal for the state. In the meantime, the development and implementation of a statewide POLST registry would present a significant opportunity for the communication of patient preferences across settings.

## Public Education and Engagement

**IOM RECOMMENDATION 5.** Civic leaders, public health and other governmental agencies, community-based organizations, faith-based organizations, consumer groups, health care delivery organizations, payers, employers, and professional societies should engage their constituents and provide fact-based information about care of people with advanced serious illness to encourage advance care planning and informed choice based on the needs and values of individuals.

Specifically, these organizations and groups should:

- ▶ Use appropriate media and other channels to reach their audiences, including underserved populations.
- ▶ Provide evidence-based information about care options and informed decisionmaking regarding treatment and care.
- ▶ Encourage meaningful dialogue among individuals and their families and caregivers, clergy, and clinicians about values, care goals, and preferences related to advanced serious illness.
- ▶ Dispel misinformation that may impede informed decisionmaking and public support for health

system and policy reform regarding care near the end of life.

In addition:

- ▶ Health care delivery organizations should provide information and materials about care near the end of life as part of their practices to facilitate clinicians' ongoing dialogue with patients, families, and caregivers.
- ▶ Government agencies and payers should undertake, support, and share communication and behavioral research aimed at assessing public perceptions and actions with respect to end-of-life care, developing and testing effective messages and tailoring them to appropriate audience segments, and measuring progress and results.
- ▶ Health care professional societies should prepare educational materials and encourage their members to engage patients and their caregivers and families in advance care planning, including end-of-life discussions and decisions.

All of the above groups should work collaboratively, sharing successful strategies and promising practices across organizations.

Most Americans are ill-prepared for the end-of-life treatment choices they will likely face for themselves or their loved ones. Fortunately, the social climate for discussions about death and dying has improved dramatically in the past several years. An example of this positive shift is the best-seller status of Atul Gawande's book *Being Mortal: Medicine and What Matters in the End*.<sup>41</sup>

### Progress

California has greatly increased awareness among consumers, providers, and government leaders about the importance of advance care planning and end-of-life care. Active grassroots networks of committed local coalitions are coordinated under a statewide umbrella organization, the Coalition for Compassionate Care of California (CCCC). Comprising volunteer physicians, nurses, social workers, and other health professionals, the coalitions have developed connections with community groups and local health providers, spreading the network of support.

Other examples of activities and approaches to support public education and engagement include the following.

**Cross-sector partnerships.** Some coalitions have established unique partnerships with local leaders and stakeholders to address community-specific needs. For example, in Sacramento County, local coalition members joined with hospitals and skilled nursing facilities on a program to improve palliative care in nursing homes and to reduce unnecessary resident transfers to acute care hospitals. California county health departments have also developed initiatives to bring together organizations and individuals from the local private, public, nonprofit and volunteer sectors to develop and expand advance care planning and palliative care in their communities.

**Faith leader engagement.** Seminars for faith communities adapted from an education program created by the Center for Healthcare Decisions in Sacramento have been offered by several local coalitions.

**Population-specific efforts.** In response to California's ethnic diversity, several local coalitions offer outreach and education in English and Spanish. In San Francisco, which has a large Chinese American population, the Chinese American Coalition for Compassionate Care (CACCC)<sup>42</sup> was formed to meet the special needs of consumers and the health providers who work with them. The Advance Care Planning Coalition at the UCLA Medical Center is piloting an advance care planning (ACP) program and registry for Santa Monica's homeless community.

**Health system efforts.** The Integrated Healthcare Association Quality of Life Conversation is a voluntary education and awareness campaign for health care organizations to educate their workforce on ACP and to provide a call to action to expand the use of advance directives. Several California health systems, including Kaiser Permanente and Sutter Health, have developed their own advance directive tools and processes, and are testing videos on ACP produced by Advance Care Planning Decisions, a nonprofit founded by physician and author Angelo Volandes.

**Media.** Many advocacy organizations and health systems in California celebrate National Healthcare Decisions Day each April 16. The event uses print, broadcast, and social media to inspire and empower individuals and their families with information and tools about the importance of

ACP. In-depth news coverage has also helped increase public awareness. Two examples are a 2012 series on aging, illness, and ACP by *Los Angeles Times* columnist Steve Lopez, and a 2013 series of articles on death and dying, the cost of prolonging life, ACP, and palliative care by Lisa Krieger in the *San Jose Mercury News*. At the conclusion of the Krieger series, the *Mercury News* and community partners convened a series of well-attended public forums on the topic around the San Francisco Bay Area.

**Tools and resources.** Those committed to ACP and palliative care in California have developed a wealth of tools and resources for consumer education and engagement. Examples include easy-to-understand advance directive forms,<sup>43</sup> playing cards<sup>44</sup> that clarify individual life goals and help with end-of-life conversations, web-based tools such as [prepareforyourcare.org](http://prepareforyourcare.org) that guide consumers through the elements of ACP, and additional tools available at [capolst.org](http://capolst.org) and [coalitionccc.org](http://coalitionccc.org). A sampling of consumer-focused tools is provided in the Appendix, Table 3.

Tools to aid health providers in educating their patients include four fact-based "decision guides"<sup>45</sup> that support discussions about treatment options during advanced serious illness, including CPR, tube feeding, artificial hydration, and ventilation.

## Gaps and Opportunities

Despite the progress, advance care planning and palliative care are not yet considered an integral part of the standard of care in California. The challenge is great because of the sheer size of the state and the multi-cultural demographic. Experts surveyed for this report suggested a number of approaches for consumer education and engagement.

**Strengthening local coalitions.** These organizations need engaged leadership and sufficient financial resources to continue to host trainings and provide brochures and other materials. Most coalitions have no paid staff — all work is completed by volunteers. New and more consistent funding sources for coalitions would strengthen their capacity. Survey respondents suggested engaging local health systems and health plans for financial support, seeking charitable giving, and obtaining additional grant funding.

### **Engaging consumers and providers further upstream.**

Too often, health professionals and consumers wait until a crisis occurs before having serious conversations about treatment preferences. Survey respondents pointed to the need to engage consumers and health providers further upstream, when people can fully express their goals of care; reach out to younger, healthier individuals and encourage them to complete advance health directives; and continue efforts to engage physicians, beyond those who deal primarily with geriatric or seriously ill patients.

**Leveraging special initiatives and events.** High-profile news stories, events, or statewide initiatives are opportunities for expanding outreach and education efforts. Just as POLST implementation provided a tipping point for expanding the conversation around advance care planning, energy around establishment of an electronic POLST registry could be leveraged to recruit new coalition participants and engage new audiences. Opportunities within national and state health care reform initiatives should also be pursued.

**Ensuring a united voice.** Effective consumer outreach and education requires the work of many individuals from state and local government, local coalitions, health organizations, health plans, faith leadership, community partnerships, and volunteers. Ideally, efforts will be unified and coordinated under a single umbrella organization. Several survey participants recommended the Coalition for Compassionate Care for this role due to its experience and success in this area.

## **Looking Ahead**

The proportion of the US population age 65 and older has more than tripled over the last century,<sup>1</sup> and the aging of the baby boomer generation means that individuals, families, and providers will encounter end-of-life care issues more and more frequently in the coming years.

The landscape will further alter after controversial new legislation, Assembly Bill (AB)x2-15, End-of-Life Options, takes effect in January 2016. Californians will be able to legally obtain medications from physicians to end their lives in certain circumstances. The health care system and stakeholders are working now to define the process to implement this option, which was signed into law in October 2015. In a state the size and diversity of

California, there will be challenges developing a uniform approach that addresses the intent behind the legislation.

As this report demonstrates, California has taken important steps toward ensuring that high-quality, compassionate, and cost-effective care is available wherever patients are. Notably, California was given a “B” grade in the CAPC 2015 state-by-state report card that rates access to inpatient palliative care services.<sup>46</sup> Among the 10 most populous states, only Ohio and New York scored better.

The activities and programs cited in this report — not an exhaustive accounting of all of the related work being done across the state — are important indications of progress that can be models for other organizations and states. But a great deal more needs to be done.

*“Although more action is still needed nationwide, these are important steps toward end-of-life care that honors Americans’ values, goals, and preferences.”*

— Victor J. Dzau, MD, president  
National Academy of Medicine  
(formerly Institute of Medicine)

California is committed to improving end-of-life care. “Making personal choices about the medical care we want at the end of our lives is very important to me,” said Diana Dooley, Secretary of California Health and Human Services Agency. She noted that thoughtful, compassionate end-of-life care is one of the key goals of Let’s Get Healthy California, the statewide effort to make California the healthiest state in the nation by 2022. “Creating opportunities for conversations with our families, our health care providers, and our community civic and elected leaders is essential to assuring that our wishes are known and honored.”

## Appendix

**Table 1. Research on Palliative Care in California**

<b>San Francisco Palliative Care Task Force</b>	<i>San Francisco Palliative Care Task Force Final Report</i> , September 2014.
<b>Public Hospitals and Palliative Care</b>	Monique Parrish, <i>In It Together: How Palliative Care Spread to All of California's Public Hospitals</i> , California HealthCare Foundation, March 2013.
<b>Palliative Care in California</b>	<i>Honoring Patients' Wishes: Expanding Palliative Care in California</i> , UC Berkeley, November 2014.
<b>Community-Based Palliative Care</b>	Kate Meyers, Kathleen Kerr, and J. Brian Cassel, <i>Up Close: A Field Guide to Community-Based Palliative Care in California</i> , California HealthCare Foundation, September 2014.
<b>Palliative Care Need/Supply</b>	Kathleen Kerr et al., <i>Uneven Terrain: Mapping Palliative Care Need and Supply in California</i> , California HealthCare Foundation, February 2015.
<b>Culture</b>	R. Griffin Coleman and Judy Thomas, <i>Gather Round: Understanding How Culture Frames End-of-Life Choices for Patients and Families</i> , California HealthCare Foundation, November 2014.
<b>Characteristics of California Palliative Care Programs</b>	M. W. Rabow, D. L. O'Riordan, and S. Z. Pantilat, "A Statewide Survey of Adult and Pediatric Outpatient Palliative Care Services," <i>Journal of Palliative Medicine</i> 17, no. 12 (December 2014): 1311-6, doi:10.1089/jpm.2014.0144. A. K. Smith et al., "The Diverse Landscape of Palliative Care Clinics," <i>Journal of Palliative Medicine</i> 16, no. 6 (June 2013): 661-8, doi:10.1089/jpm.2012.0469. S. Z. Pantilat et al., "Characteristics of Palliative Care Consultation Services in California Hospitals," <i>Journal of Palliative Medicine</i> 15, no. 5 (May 2012): 555-60, doi:10.1089/jpm.2011.0390.



## Appendix, continued

**Table 2. State Legislation, Regulation, and Demonstration Programs**

<b>AB 892</b> (enacted 2000)	Requires health plans to include hospice as a basic health care service.
<b>HMOs and Hospice</b> (2001)	California Department of Managed Health Care requires all health maintenance organizations to offer hospice care at levels at least equivalent to those of Medicare.
<b>California Hospital Initiative in Palliative Services</b> (enacted 2001)	The CHIPS program was a two-year, statewide initiative to increase the number of hospital-based palliative care services in California. Interdisciplinary teams from 38 hospitals participated in an innovative, longitudinal educational intervention to help hospitals establish palliative care programs.
<b>AB 1745</b> (enacted 2006)	The California Department of Health Care Services, Children’s Medical Services Branch, and the Medi-Cal program partnered with the Centers for Medicare & Medicaid Services to develop a pediatric palliative care waiver for the children of California.
<b>The Partners for Children (PFC) demonstration project</b>	This pediatric palliative care program under Medi-Cal enables children with certain advanced medical conditions to receive concurrent disease-directed care and palliative care. PFC is currently available in 9 California counties — Fresno, Los Angeles, Marin, Monterey, Orange, San Francisco, Santa Clara, Santa Cruz, and Sonoma. Facilitated through a Home and Community-Based Federal Waiver, PFC was extended through 2017. California Children’s Services plans to expand the program to up to 14 additional counties during this period.
<b>Let’s Get Healthy California report</b>	Established by Governor Brown’s Executive Order (B-19-12), the Let’s Get Healthy California Task Force developed a 10-year blueprint for improving health, controlling health care costs, promoting personal responsibility, and advancing health equity for Californians. With a focus on the triple aim of better health, better care, and lower costs, the report set six goals, each with several focused priorities, and indicators by which to measure success. One of the six goals was “End of Life: Maintaining Dignity and Independence.”
<b>SB 1004</b> (passed in 2014)	This law requires Medi-Cal to establish palliative care standards and technical assistance for MediCal managed care plans, which serve more than half of all people in the MediCal program.
<b>AB 2139</b> (passed in 2014)	This law requires health care providers, when making a diagnosis of terminal illness, to notify patients or their guardian/agent of the right to comprehensive information and counseling regarding end-of-life care options.
<b>1115 Medi-Cal Waiver: A Bridge to Reform</b> (2015)	California’s current 1115 waiver demonstration ends October 31, 2015. To meet the health care needs of the state, California has submitted a new plan proposal with four primary goals, several of which incorporate palliative care: <ul style="list-style-type: none"> <li>▶ Strengthen primary care delivery and access</li> <li>▶ Avoid unnecessary institutionalization and services by building the foundation for an integrated health care delivery system that incentivizes quality and efficiency</li> <li>▶ Address social determinants of health</li> <li>▶ Use California’s sophisticated Medicaid program as an incubator to test innovative approaches to whole-person care</li> </ul>
<b>SB 19</b> (2015)	This law establishes the California POLST eRegistry Pilot that would enable health care providers to electronically submit and access patients’ orders for end-of-life health care, ensuring immediate access to this critical information.
<b>AB 637</b> (2015)	This law authorizes nurse practitioners and physician assistants, under the direction of a physician and within their scope of practice, to sign POLST forms and make them actionable medical orders. The bill goes into effect on January 1, 2016.
<b>ABx2-15</b> (2015)	The End-of-Life Options bill would permit a “competent, qualified individual” who is an adult with a terminal disease to receive a prescription for an aid-in-dying drug if certain specific conditions are met. The bill’s provisions would end on January 1, 2026 unless extended by new legislation.

## Appendix, continued

**Table 3. Consumer-Focused Education Tools and Resources**

<p><b>Easy to Read Advance Directive</b>  <a href="http://www.iha4health.org">www.iha4health.org</a></p>	<p>Written in plain language, this Advance Health Care Directive form (available in English, Russian, Spanish, Tagalog, Vietnamese, Farsi, Korean, Armenian, and Khmer) is intended to be read and understood easily, even by those who are unable to grasp complex legal language or who have limited reading skills. Developed by the Institute for Healthcare Advancement.</p>
<p><b>Advance Health Care Directive Kit</b>  <a href="http://www.cmanet.org">www.cmanet.org</a></p>	<p>Available through the California Medical Association in English and Spanish.</p>
<p><b>Life Care Planning</b>  <a href="http://kaiserpermanente.org">kaiserpermanente.org</a></p>	<p>A program developed by Kaiser Permanente for its members, with brochures and web-based information on advance care planning.</p>
<p><b>Finding Your Way</b>  <a href="http://coalitionccc.org">coalitionccc.org</a> (PDF)</p>	<p>An educational brochure developed by CCCC for those starting the advance care planning process or considering whether to initiate or withdraw life-sustaining treatment. Also available in Spanish.</p>
<p><b>Mrs. Lee’s Story</b>  <a href="http://coalitionccc.org">coalitionccc.org</a> (PDF)</p>	<p>An introduction to end-of-life issues that concern Chinese elders and their families. Developed by CCCC. Brochure includes both Chinese and English text.</p>
<p><b>Go Wish Cards</b>  <a href="http://www.gowish.org">www.gowish.org</a></p>	<p>The Go Wish cards, developed by the Coda Alliance, are a deck of cards that provide an easy, entertaining way to think and talk about what’s important to you if you become seriously ill. Play the game online or order the card decks.</p>
<p><b>Heart-to-Heart Cards</b>  <a href="http://www.caccc-usa.org">www.caccc-usa.org</a></p>	<p>Developed by the Chinese American Coalition for Compassionate Care, the Heart-to-Heart cards are designed to facilitate communication about issues surrounding the end of life.</p>
<p><b>Talking It Over</b>  <a href="http://coalitionccc.org">coalitionccc.org</a> (PDF)</p>	<p>Talking It Over is a guide to facilitating discussion among informal groups — such as congregations, community organizations, classes, or senior groups — to explore personal views about end-of-life care. Though this discussion guide can be used by experienced facilitators and health care professionals, it is designed and written so that anyone can use it. Developed by CCCC.</p>
<p><b>Thinking Ahead</b>  <a href="http://coalitionccc.org">coalitionccc.org</a> (PDF)</p>	<p>An advance directive workbook and DVD created by CCCC. This advance directive contains words, symbols, and pictures that facilitate discussion and decisionmaking regarding values, goals, and treatment preferences at the end of life. The video serves as an instruction manual, containing vignettes that illustrate in simple, graphic format the purpose and use of the materials.</p>
<p><b>Thinking Ahead Matters</b>  <a href="http://coalitionccc.org">coalitionccc.org</a> (PDF)</p>	<p>This white paper explores the concepts around conservatorship of people with developmental disabilities, with an aim of fostering greater self-determination and empowerment of this population throughout life as well as at the end of life.</p>
<p><b>CoalitionCCC.org</b>  <a href="http://coalitionccc.org">coalitionccc.org</a></p>	<p>The website of the CCCC provides consumer-focused advance care planning resources, information on POLST, and a video library.</p>
<p><b>CaPOLST.org</b>  <a href="http://capolst.org">capolst.org</a></p>	<p>CaPOLST.org offers consumers access to a variety of tools and information related to POLST, including a downloadable POLST form translated into 12 languages and Braille, a POLST guide, FAQs, and videos demonstrating POLST conversations.</p>
<p><b>Prepare for Your Care</b>  <a href="http://www.prepareforyourcare.org">www.prepareforyourcare.org</a></p>	<p>PREPARE is a web-based program that helps consumers make medical decisions, talk with their doctors, and get the medical care that is right for them. Developed by The Regents of the University of California.</p>

## Endnotes

1. *Dying in America*, Institute of Medicine, September 17, 2014, [iom.nationalacademies.org](http://iom.nationalacademies.org).
2. The Institute of Medicine is now the National Academy of Medicine.
3. The Berkeley Forum is recognized for its 2015 report *Drivers of Health Expenditure Growth in California*, in which it made two principal recommendations to bend the health care cost curve in California — to increase use of palliative care and to support an increase in people’s physical activity. The report is available at [berkeleyhealthcareforum.berkeley.edu](http://berkeleyhealthcareforum.berkeley.edu) (PDF).
4. *Healthcare Leaders and Berkeley Policy Experts Issue Report on Honoring Patients’ Wishes by Expanding Palliative Care in California*, Berkeley Forum, November 2014, [berkeleyhealthcareforum.berkeley.edu](http://berkeleyhealthcareforum.berkeley.edu).
5. Monique Parrish, *In It Together: How Palliative Care Spread to All of California’s Public Hospitals*, California HealthCare Foundation, March 2013, [www.chcf.org](http://www.chcf.org).
6. Kate Meyers, Kathleen Kerr, and J. Brian Cassel, *Up Close: A Field Guide to Community-Based Palliative Care in California*, California HealthCare Foundation, September 2014, [www.chcf.org](http://www.chcf.org).
7. “How to Launch a Palliative Care Task Force in Your City or County: Free Webinar on December 10, 2014,” Coalition for Compassionate Care of California, [www.coalitionccc.org](http://www.coalitionccc.org).
8. Roxanne Moster and Enrique Rivero, “Southern California Health Care Providers Call for More Compassionate End-of-life Care,” UCLA Newsroom, May 22, 2014, [newsroom.ucla.edu](http://newsroom.ucla.edu); Kate O’Malley, “Partnering for Palliative Care in California,” CHCF Blog, June 4, 2015, [www.chcf.org](http://www.chcf.org).
9. “Payer-Provider Partnerships to Expand Community-Based Palliative Care,” California HealthCare Foundation, December 2014, [www.chcf.org](http://www.chcf.org); Kate O’Malley, “Partnering for Palliative Care in California,” CHCF Blog, June 4, 2015, [www.chcf.org](http://www.chcf.org).
10. Personal communication with Marvin Gordon, MD, Regional Medical Director, Health Net of California, June 29, 2015.
11. Personal communication with Ann Zisser, RN, Clinical Program Director – Oncology Strategy and Innovation, Anthem, June 25, 2015.
12. Kathleen Kerr et al., “Uneven Terrain: Mapping Palliative Care Need and Supply in California,” California HealthCare Foundation, February 2015, [www.chcf.org](http://www.chcf.org).
13. “California’s Medi-Cal Pediatric Palliative Care Benefit (Partners for Children),” Children’s Hospice & Palliative Care Coalition, accessed July 30, 2015, [www.chpcc.org](http://www.chpcc.org).
14. Mary H. Michal et al., *Corporate Practice of Medicine Doctrine: 50 State Survey Summary*, Center to Advance Palliative Care and the National Hospice and Palliative Care Organization, September 2006, [www.nhpco.org](http://www.nhpco.org) (PDF).
15. Constance Dahlin, ed., *Clinical Practice Guidelines for Quality Palliative Care 3rd ed.* 2013, National Consensus Project, 2013, [www.nationalconsensusproject.org](http://www.nationalconsensusproject.org); “NCCN Guidelines,” National Comprehensive Cancer Network, accessed July 9, 2015, [www.nccn.org](http://www.nccn.org); *A National Framework and Preferred Practices for Palliative and Hospice Care Quality*, National Quality Forum, December 2006, [www.qualityforum.org](http://www.qualityforum.org); *National Voluntary Consensus Standards for Palliative Care and End-of-Life Care*, National Quality Forum, April 2012, [www.qualityforum.org](http://www.qualityforum.org); “Measuring What Matters,” American Academy of Hospice and Palliative Medicine, accessed July 9, 2015, [www.aahpm.org](http://www.aahpm.org).
16. *A National Framework*, National Quality Forum; *National Voluntary Consensus Standards*, National Quality Forum.
17. “Measures Overview,” ASCO Institute for Quality, [www.instituteforquality.org](http://www.instituteforquality.org).
18. *Clinical Practice Guidelines*, National Consensus Project.
19. “Measuring What Matters,” American Academy of Hospice and Palliative Medicine.
20. “Opinion 2.191 — Advance Care Planning,” American Medical Association, [www.ama-assn.org](http://www.ama-assn.org).
21. “Pioneering Health Care Organizations Pledge to Become ‘Conversation Ready,’” Institute for Healthcare Improvement, accessed July 7, 2015, [www.ihl.org](http://www.ihl.org).
22. “UC Health Helps ICU Nurses Bring Palliative Care to Patients,” UCSF, September 2013, [scienceofcaring.ucsf.edu](http://scienceofcaring.ucsf.edu).
23. “Welcome to eDoctoring,” UC Davis, accessed July 7, 2015, [edoc.ucdavis.edu](http://edoc.ucdavis.edu); “Innovative Education Program for End-of-Life Care Now Online,” UC Davis, January 18, 2012, [www.ucdmc.ucdavis.edu](http://www.ucdmc.ucdavis.edu).
24. Chinese American Coalition for Compassionate Care, accessed July 21, 2015, [www.caccc-usa.org](http://www.caccc-usa.org).
25. Cynthia Roat, Anne Kinderman, and Alicia Fernandez, *Interpreting in Palliative Care: A Continuing Education Workshop*, California HealthCare Foundation, November 2011, [www.chcf.org](http://www.chcf.org).
26. V. J. Periyakoil, *Doctors Struggle with Conducting End-of-Life Conversations with Their Patients*, Stanford School of Medicine, [aging.stanford.edu](http://aging.stanford.edu).
27. Monique Parrish, Anne Kinderman, and Michael Rabow, *Weaving Palliative Care Into Primary Care: A Guide for Community Health Centers*, California HealthCare Foundation, August 2015, [www.chcf.org](http://www.chcf.org).
28. “Continuing Medical Education,” Medical Board of California, accessed July 7, 2015, [www.mbc.ca.gov](http://www.mbc.ca.gov).
29. Data from Dawn M. Leveau, director, workforce and leadership development, American Academy of Hospice and Palliative Medicine, via personal communication with Kate Meyers, September 25, 2015.

30. Diane Meier, "IOM Report Calls for Transformation of Care for the Seriously Ill," Health Affairs Blog, September 24, 2014, [www.healthaffairs.org/blog](http://www.healthaffairs.org/blog).
31. Tricia McGinnis, Maia Crawford, and Stephen A. Somers, *A State Policy Framework for Integrating Health and Social Services*, The Commonwealth Fund, July 2014, [www.commonwealthfund.org](http://www.commonwealthfund.org) (PDF).
32. Maia Crawford and Rob Houston, *State Payment and Financing Models to Promote Health and Social Service Integration*, Center for Health Care Strategies, February 2015, [www.chcs.org](http://www.chcs.org) (PDF).
33. David Muhlestein, "Accountable Care Growth in 2014: A Look Ahead," Health Affairs Blog, January 29, 2014, [www.healthaffairs.org/blog](http://www.healthaffairs.org/blog).
34. "Growth and Dispersion of Accountable Care Organizations: June 2014 Update," Leavitt Partners, June 12, 2014, [www.leavittpartners.com](http://www.leavittpartners.com).
35. Meier, "IOM Report."
36. "What Is PACE?" National PACE Association, accessed July 30, 2015, [www.npaonline.org](http://www.npaonline.org).
37. "Health Care Innovation Awards: California," Centers for Medicare & Medicaid Services, accessed July 23, 2015, [www.innovation.cms.gov](http://www.innovation.cms.gov).
38. "PCQN by the Numbers," Palliative Care Quality Network, accessed July 15, 2015, [www.pcqn.org](http://www.pcqn.org).
39. "Health Care Innovation Awards: California," CMS.
40. "Physician Orders for Life-Sustaining Treatment," Coalition for Compassionate Care of California, accessed July 23, 2015, [www.coalitionccc.org](http://www.coalitionccc.org).
41. Atul Gawande, *Being Mortal: Medicine and What Matters in the End* (New York: Metropolitan Books, 2014).
42. Chinese American Coalition for Compassionate Care.
43. "Easy to Read California Advance Directive," Institute for Healthcare Advancement, [www.ih4health.org](http://www.ih4health.org).
44. "The Go Wish Game," Coda Alliance, [www.gowish.org](http://www.gowish.org).
45. "Decision Guides for Healthcare Providers," Coalition for Compassionate Care of California, [www.coalitionccc.org](http://www.coalitionccc.org).
46. *America's Care of Serious Illness: 2015 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals*. Center to Advance Palliative Care and the National Palliative Care Resource Center, [reportcard.capc.org](http://reportcard.capc.org).