



CALIFORNIA HEALTHCARE FOUNDATION



**Advance Care Planning Takes Root:
Best Practices from Four California
Communities**

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About the Author

Anne Boyd Rabkin, MPA, is a communications and program management consultant specializing in public health, health care, and global health issues.

About the Foundation

The **California HealthCare Foundation** works as a catalyst to fulfill the promise of better health care for all Californians. We support ideas and innovations that improve quality, increase efficiency, and lower the costs of care. For more information, visit www.chcf.org.

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Introduction

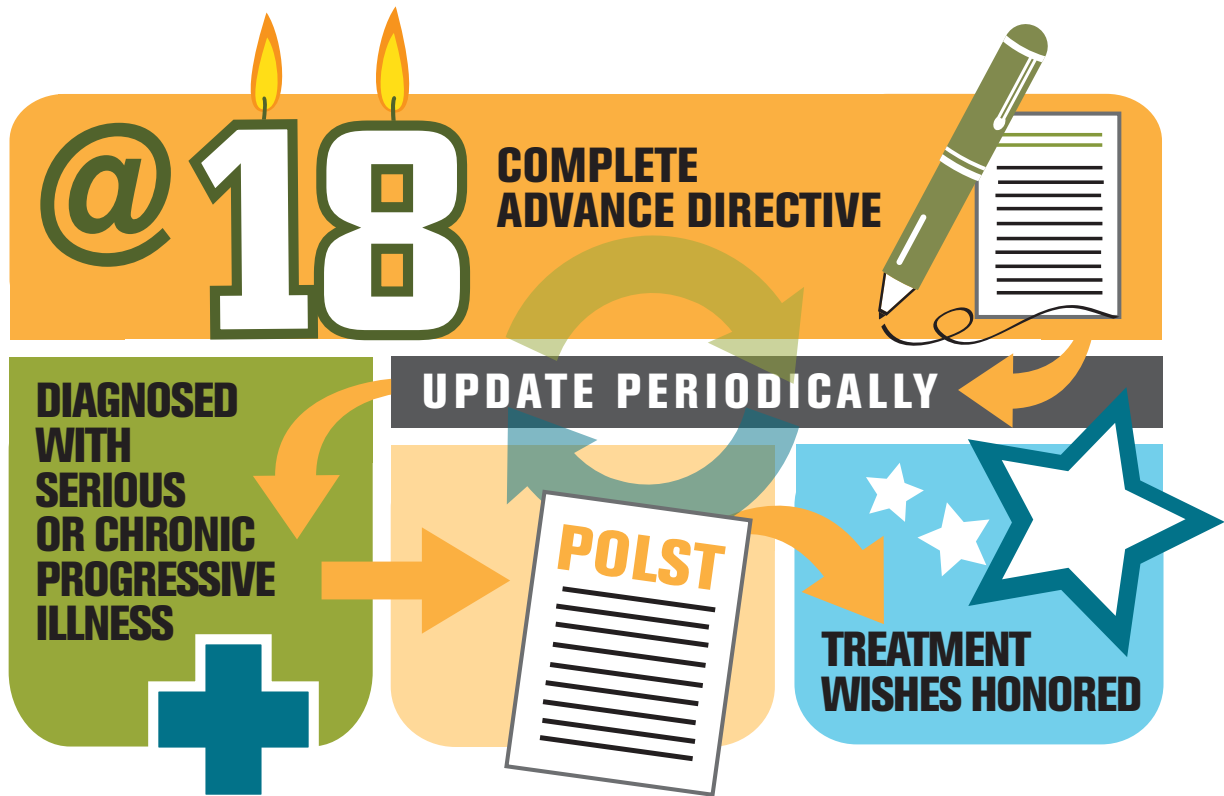
A 2009 survey confirmed the anecdotal experiences of many end-of-life care advocates: Most Californians said they would prefer to die at home, but only 32% of deaths occurred at home that year.¹ A large percentage of survey respondents said it was important to put their end-of-life care wishes in writing, yet only 23% said they had done so.²

To address this continuing challenge in California, regional coalitions — which included hospitals, skilled nursing facilities, emergency medical service providers, hospices, nursing homes, senior centers, and consumer groups — formed in the late 1990s and early 2000s to promote advance care planning through a community-based approach. Advance care planning is a process to help patients consider options and establish their wishes

about future care in legal documents that take effect when those patients lose the capacity to make decisions for themselves. These coalitions readily embraced the Physician Orders for Life-Sustaining Treatment (POLST) process when it was first introduced to California in 2007.

To better understand successful community engagement strategies for advance care planning, the California HealthCare Foundation (CHCF) interviewed 10 coalition members in four California communities: Inland Empire, Sacramento Area, Santa Cruz County, and Sonoma County. (See Appendix A for a list of interviewees.) This paper describes the experiences and lessons learned from these coalitions in implementing successful advance care planning and POLST initiatives.

Figure 1. Advance Care Planning Continuum for Individuals



Source: Modeled after a diagram developed by Mad*Pow and the Coalition for Compassionate Care of California.

Two Decades of Action: Advance Care Planning and POLST

1995. Oregon pilots the first POLST program.

1994–1997. The Extreme Care, Humane Options (ECHO) Project in Sacramento, sponsored by the Center for Healthcare Decisions (CHCD), brings together community members and health care professionals to develop recommendations for hospitals to improve end-of-life care. ECHO becomes a national model of community collaboration.

1998. Building on the ECHO project, the Coalition for Compassionate Care of California (CCCC) is established with funding from the Robert Wood Johnson Foundation to promote improvements in end-of-life care for Californians through consumer engagement, professional education, and policy changes.

2000. Bill Moyers' PBS series "On Our Own Terms: Moyers on Dying" stimulates national debate on end-of-life issues and highlights the emergence of volunteer advance care planning coalitions, including several in California.³

2004. The National POLST Paradigm Initiative Task Force is established with leaders from early adopter states: Oregon, New York, Pennsylvania, Washington, West Virginia, and Wisconsin.

2007. CHCF funds CCCC to launch a statewide POLST coalition, and also funds eight local coalitions around California to participate.

2009. State Assembly Bill 3000 takes effect on January 1, 2009, amending the California Probate Code and requiring all health care professionals and providers — including hospitals, nursing facilities, and first responders — to honor POLST orders. The number of local POLST coalitions in California grows to 18.

2010. The number of local POLST coalitions in California grows to 26.

2012. CHCF publishes the results of a statewide survey in *Final Chapter: Californians' Attitudes and Experiences with Death and Dying*.

Regional Advance Care Planning Coalitions

By using collaborative, community-based strategies to raise awareness about advance care planning approaches, health care providers are better able to support patients at the end of life. The community coalitions profiled in this paper have long-standing experience promoting advance care planning; when POLST was introduced in 2007, it was natural for these coalitions to expand their focus to include this new process. Best practices described here were initially established to promote advance care planning, and with the advent of POLST, coalitions broadened their memberships and honed their strategies.

- ▶ **The Riverside/San Bernardino Coalition** covers the Inland Empire, a region in Southern California including Riverside and San Bernardino Counties and stretching from east of Los Angeles to the Arizona border. The Riverside/San Bernardino coalition expanded on the work of the Inland Empire Palliative Care Coalition (IEPCC), which works to educate, promote, and expand awareness of palliative care programs and providers in their region. This coalition was the first to pilot POLST in California in 2007.
- ▶ **The Sacramento Area Coalition** has a deep history of promoting advance care planning locally and statewide. In the mid-1990s, the Center for Health Care Decisions (known then as Sacramento Healthcare Decisions), launched its Extreme Care, Humane Options (ECHO) Project. This effort brought together nearly 1,000 community members and health care professionals in a three-year endeavor to develop recommendations for hospitals to improve end-of-life care. The ECHO Project became a national model of community collaboration and led to the creation of the Coalition for Compassionate Care of California (CCCC), a statewide partnership promoting high-quality, compassionate end-of-life care. CCCC is the lead organization for statewide POLST efforts in California. In 2009, the Sacramento Area Coalition integrated POLST activities.
- ▶ **The Santa Cruz County Coalition** is coordinated by Hospice of Santa Cruz County. It draws on the decade of experience of the Santa Cruz County End-of-Life Coalition's "Make Your Wishes Known"

Background on California POLST Coalitions

POLST originated in Oregon in the mid-1990s, and today all but a handful of states have POLST activities taking hold.⁴ The POLST program, designed to improve the quality of care for people with advanced illness or who are extremely frail, involves effective communication of patient wishes, clear documentation of medical orders, and the assurances of health care professionals to honor these wishes. (POLST forms complement, but do not replace, advance directives.)

In 2007 CHCF spearheaded efforts to bring POLST to California. Between 2007 and 2013, CCCC, with support from CHCF, led a statewide POLST implementation effort that now includes 27 local POLST coalitions.⁵ CCCC has executed statewide strategies to pass legislation, establish a statewide POLST Task Force, and develop standardized implementation tools. The POLST Task Force brought together 30 organizations from around California representing health care providers across the continuum of care to address state policy, messaging, and training on POLST and end-of-life issues.

The local POLST coalitions have established community partnerships to implement POLST across care settings: in hospitals, nursing homes, hospices, skilled nursing facilities, and senior centers. The coalitions have engaged key stakeholders and local leaders; provided education and training on POLST; and served as a resource for information and problem-solving at the operational level. In 2009, the year POLST first went into effect in California, local coalitions gave nearly 800 presentations on POLST around the state to providers, patients, family members, and community organizations, such as local chapters of the Alzheimer's Association. By 2014, more than 700 individuals from across the state had participated in the POLST train-the-trainer program.

While California was not the first state to explore a coalition approach to implementing POLST, it was the first state to establish a robust grassroots, collaborative approach, and to develop such a widespread local coalition strategy. While some of the early POLST programs in other states were housed at academic medical centers with one primary leader, the leadership in California is shared across multiple organizations, both in local coalitions and with CCCC's statewide POLST work.

California's POLST coalitions have served as a catalyst for increasing awareness and understanding about the importance of advance care planning. With its emphasis

on patient and physician communication about treatments, the POLST program added credibility to advance care planning among physicians, increased both provider and consumer awareness and comfort with discussing end-of-life care issues, and stimulated the movement toward culture change in the health care community, from a culture of focusing on a cure to focusing on the patient's wishes. Communication between providers, patients, and family members about POLST and advance directives has started to become the standard of care.

Interviewees described this cultural shift:

"With the POLST initiative across California, it has brought everyone under one big umbrella and made palliative medicine legitimate. I remember when we first started [this work]; it was really a lonely situation where there was a lot of rejection from physicians.... Palliative care is a team approach and physicians like to be in control, so previously they tended to be territorial and reject this approach. But that culture has changed. Now I think they see that [advance care planning] is here to stay."

— Dr. Tarek Mahdi
Inland Empire Palliative Care Coalition

"POLST has had a big impact because it goes across the full continuum of care and got the attention of the whole health care system. [The statewide initiative] had the [right] local and statewide pieces: a comprehensive approach with 27 groups working around the state to get this into their communities."

— Judy Citko
Coalition for Compassionate Care of California

initiative, a joint effort of the Health Improvement Partnership of Santa Cruz County and Hospice of Santa Cruz County. The “Make Your Wishes Known” initiative works with community educators, physicians, and other care providers to promote completion of advance directives. The project has disseminated thousands of referral cards about how and why community members should complete their advance directive; staffs an advance care planning information phone line; and works with Hospice of Santa Cruz County and the End-of-Life Coalition to train health care professionals, community groups, and local businesses about the importance of the forms. The coalition added POLST activities in 2009.

- ▶ **The Sonoma County Coalition**, also known as the Journey Project Coalition, is led by the Community Network Journey Project. The Journey Project has been advocating for advance care planning, palliative care, and affordable community-based long term care in Sonoma County since the early 1990s. Its signature workshop for consumers, “Wellness Through Life’s End: Planning and Navigating the Journey,” provided in English and Spanish, has educated more than 2,000 community members.

While these regions vary in their geography, demographics, population size, and health care system structure, the coalitions in each region were all successful in raising awareness and building highly collaborative coalitions. All have successfully engaged and educated health professionals and consumers about the need for advance care planning and the resources available to support it. Likewise, all of these coalitions have developed a similar model of shared leadership and ownership as well as a collaborative spirit:

“[These coalitions have] been successful because they created true coalitions — more than just convening people from different organizations; it’s creating a collaborative body that moves forward for the greater interest of the larger group and has that shared commitment and vision with individual members having a sense of ownership. It’s not just one organization driving it with partners.”

— Judy Citko
Coalition for Compassionate Care of California

End-of-Life Care Terms Defined

Advance care planning is the process of learning about the types of decisions that might need to be made, considering those decisions ahead of time, then letting others know about these preferences, often by putting them into an advance directive, a legal document.⁶ This process can include end-of-life planning, but can take place at any time during a person’s life.

Advance directives are legal documents to spell out end-of-life care decisions for family members, friends, and health care professionals to avoid confusion.⁷ Advance directives are ideally filled out while patients are healthy and can think about the end-of-life care they would want. With an advance directive, individuals can also choose someone to make medical decisions for them. The directives go into effect when patients are unable to speak for themselves.⁸

End-of-life planning includes making choices about end-of-life care goals, where the patient wishes to receive that care, and which treatments and what kind of care the patient wishes to receive.⁹ It includes plans for palliative and hospice care.

Hospice care is end-of-life care provided by a team of health care professionals and volunteers who give medical, psychological, and spiritual support. The goal of hospice care is to help people die in peace and comfort, and with dignity.¹⁰

Palliative care is the treatment of the discomfort, symptoms, and stress of serious illness. It can also address the side effects of medical treatments. Hospice care always includes palliative care; however, palliative care can be provided at any stage of an illness. The goal of palliative care is to make patients comfortable and improve their quality of life.¹¹

POLST (Physician Orders for Life-Sustaining Treatment) is a physician’s order that gives patients more control over their end-of-life care. Produced on a distinctive bright pink form and signed by both the doctor and patient, POLST specifies the types of medical care that a patient wishes to receive at the end of his or her life. In so doing, POLST prevents unwanted or inappropriate care, reduces patient and family suffering, and ensures that patients’ wishes are honored at the end of life.¹²

Building Blocks of Success

In promoting advance care planning in their communities, the four coalitions highlighted in this paper shared common successful approaches as well as challenges. Overall, the California coalitions' grassroots, collaborative approach differed from other advance care planning implementation efforts nationwide. The four highlighted coalitions used similar strategies to promote advance care planning in their communities.

Common best practices, described further below, included:

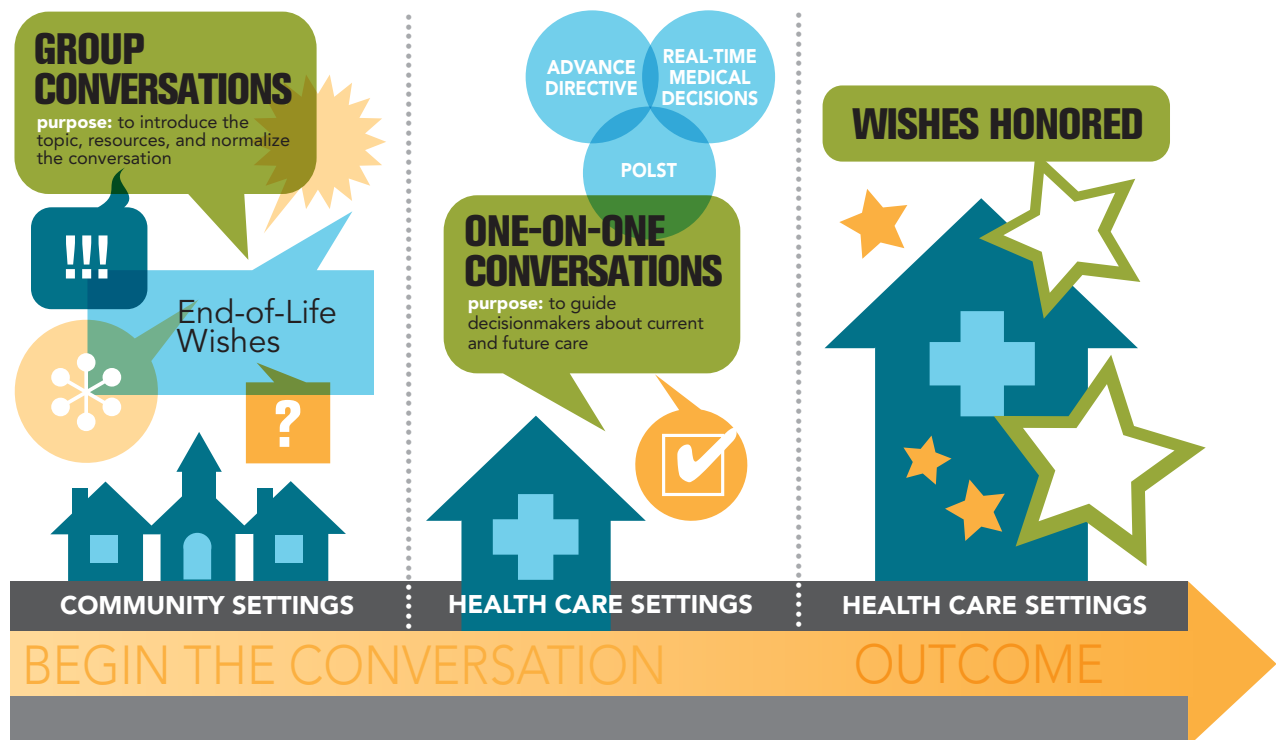
- ▶ Identifying strategic leaders and existing champions
- ▶ Creating an independent organization
- ▶ Outreach to both providers and consumers
- ▶ Working with faith leaders
- ▶ Conducting multilingual and multicultural outreach

Involving Leaders and Stakeholders

While the make-up of each community and health care system varied, a key element of establishing a successful coalition was having a thoughtful and strategic process of engaging leaders. This included acknowledging and engaging those who have already been working on advance care planning — for example, hospital social workers, volunteers, and faith leaders outside of the health care system — and ensuring that their knowledge and experiences were incorporated into new initiatives.

As local advance care planning coalitions formed, they engaged a wide range of professionals and community members. In Sonoma County, for example, the Journey Project brought together retired professionals who recognized the importance of improving end-of-life care, including a former county supervisor, retired nurse educator, and former head of an assisted living association. Similarly, the Santa Cruz coalition was started by professionals experienced in working with the elderly, such as senior residence activity coordinators, church

Figure 2. Model of an Effective Advance Care Planning System



Source: Modeled after a diagram developed by the Coalition for Compassionate Care of California.

representatives, hospice staff, hospital case managers, hospital chaplains, retired physicians, and gerontology students.

When POLST was part of advance care planning efforts, having a physician champion proved critical to building understanding about POLST in the medical community. This was a key leadership position for each coalition as they promoted POLST. This role, however, has not been as crucial for the promotion of advance care planning more broadly, which involves a wider range of practitioners across the continuum of care.

Community advocates with a passion and commitment for end-of-life issues were important members of the coalitions. Almost all of the coalition representatives interviewed mentioned that their end-of-life programs began as discussion groups over bioethics issues. Hospitals face sticky legal situations when patients' wishes are not documented; some family members want to apply all medical options in the face of a loved one's death, while others want to minimize hospitalization and treatment.

While health care communities struggled with local cases, particularly dramatic cases drew national attention to the issue in the 1990s and 2000s. For example, the highly publicized case of Terry Schiavo, who remained on life support for 15 years while her family members struggled over removing her feeding tube, turned her husband into a staunch advocate for advance care planning. As ethics discussion groups formed over these situations, the most active participants emerged as volunteer leaders and key spokespeople on advance care planning issues. Newly forming coalitions can look to leaders in their communities who have taken on this ethical debate.

An Independent Organization as Common Ground

The POLST and advance care planning coalitions served as a critical common ground for health care systems to address challenging end-of-life issues together. In the Inland Empire, for example, two hospitals had palliative care programs and both struggled with similar end-of-life issues, but there was previously not a venue for them to share experiences. As competing hospitals, they were unlikely to discuss their challenges and solutions outside of the coalition infrastructure.

“At the coalition meetings, we sat together to discuss how to address end-of-life challenges. Working independently we wouldn't come up with solutions, but working together we created community-wide solutions.”

— Dr. Tarek Madhi
Inland Empire Palliative Care Coalition

Having an independent, nonprofit organization, which is not competing with health care facilities for business, to lead the effort was considered key to progress and collaboration across the health care community. The structure of each coalition varied from region to region, but one common feature was a steering committee or coordinating council comprised of passionate champions of advance care planning. These champions were health care providers, faith leaders, and government agency personnel, and while they brought their professional experiences to the coalition, interviewees noted that champions did not participate on behalf of or promote their employers as part of coalition participation. Most champions participated on their own time as volunteers.

Another common feature of the coalitions was an inclusive spirit: Participation was welcomed by any community group that wished to address end-of-life issues. One coalition member noted:

“The reach of the coalition is not limited by the members sitting at the steering committee table.”

— Eleanor Littman
Health Improvement Partnership of Santa Cruz County

Interviewees agreed that the coalitions provided a suitable environment for providers to obtain training, share experiences, and build community-wide relationships. Through this grassroots, collaborative approach, coalition partners shared ownership and leadership with a clear vision for determining what is best for patients and how to make their wishes known — independent of the influences of market competition.

Targeting Providers and Consumers

The most successful advance care planning efforts involved targeted outreach to health care providers and consumers.

Engaging and Training Providers

Coalitions engaged health care providers across the continuum of care — including hospitals, skilled nursing facilities, hospices, and nursing homes — in discussions about end-of-life issues and in trainings on how to use POLST and how to have advance care planning conversations with patients. Coalition members stressed the importance of equipping providers with the skills to discuss sensitive end-of-life issues and to be able to tailor those conversations to the needs and desires of their patients.

Some coalitions held ethics discussions, lectures, and workshops for providers throughout the health care community as well as with professionals working with the elderly outside of the health care arena, such as at senior centers. These opportunities promoted open conversation and exploration of challenges in addressing end-of-life issues. As providers attended these discussions on a volunteer basis, several interviewees pointed out the importance of holding meetings at lunchtime or in the evening to make attendance easier.

Some successful programs incorporated advance care planning training into continuing medical education certification and residency program requirements to motivate providers to participate. For example, the Santa Rosa Family Medicine Residency Program in Sonoma County added an advance care planning rotation to its training program, and the ICU Nursing Residency Program at the Riverside County Regional Medical Center in the Inland Empire included a POLST and palliative care training requirement. On the other hand, the Inland Empire coalition dropped its CME program because not enough physicians were attending the sessions. Their trainings continued, however, and were well-attended by nurses and nursing home staff.

Increasingly, health systems have included training on palliative care, advance directives, POLST, and end-of-life conversation skills into their new employee orientations. This tactic addresses the challenge of high turnover among health care professionals — and ensures that new providers are familiar with end-of-life issues and tools.

Meeting Consumers Where They Are

A successful strategy for reaching consumers and patients has been having conversations about end-of-life issues with groups of people who are already familiar with each other. Coalitions conducted meetings, workshops, and outreach at community centers, senior centers, and churches, among other gathering places.

Each year since 2011, on April 16 — National Health Care Decisions Day — the Santa Cruz coalition has held a forum called “Planning Ahead for Peace of Mind” at churches and senior centers with presentations on advance health care planning and related topics, such as estate and financial planning. These forums are open to the general public, offered in English and in Spanish, and advertised in the local paper. Follow up one-on-one appointments are offered, during which people can complete advance directives. Through this effort, the Santa Cruz coalition has reached nearly 200 people per year, at two dozen churches, senior centers, and senior residences throughout the county. An average of 75 people each year have left the one-on-one sessions with completed advance directives.

Through programs such as Santa Cruz’s, coalitions have stimulated community dialogue outside of the health care environment about the importance of having health directives, and have educated consumers on their choices and available resources. A ripple effect has also been observed where consumers who are educated about advance care planning have spread the word to others. One coalition member talked about the viral impact of community outreach:

“The ripple effect is profound. I ran into a lady while shopping and she told me that from what she learned from us she had already helped several friends who were going through serious illness and ending of life. It is transformative work. Helping people get their bearings and oriented so they know what good care looks like and how to go after it...for themselves or those they love.”

— Susan Keller
Community Network Journey Project

Laying the Groundwork in Advance Care Planning

In the mid-1990s the Center for Healthcare Decisions, known then as Sacramento Healthcare Decisions, conducted an ambitious community dialogue project, called the Extreme Care, Humane Options (ECHO) Project, to develop recommendations for hospitals to improve end-of-life care.

This effort brought together nearly 1,000 community members and health care professionals in four Sacramento area counties and involved more than 90 public discussion groups. Medical committees covering specialty areas such as adult intensive care, long term care, and neonatology also met regularly.

The resultant community recommendations included strategies for improving communication about treatment decisions, widening the range of health care providers involved, indicators for offering comfort care, and goals and strategies for acute care facilities. Almost every hospital in the four-county Sacramento region adopted the recommendations and instituted changes in their policies, practices, and programs. The recommendations gained widespread attention, and the ECHO Project became a national model of community collaboration.

After releasing these community recommendations, the Center for Healthcare Decisions (CHCD) convened a statewide ECHO long term care task force to develop end-of-life recommendations for skilled nursing facilities. The task force became the core group that formed the Coalition for Compassionate Care of California (CCCC), a statewide partnership promoting high-quality, compassionate end-of-life care. CCCC is the lead organization for statewide POLST efforts in California.

Engaging Faith Leaders

By collaborating with community leaders — particularly faith leaders — coalition health care providers were able to better understand their patients' beliefs, enhancing their ability to support a communication process that helped patients make their wishes clear to their loved ones and to their physicians.

For example, the Inland Empire coalition worked with Jehovah's Witness leaders who served as medical advisors to their congregants. When providers were confronted with an ethical dilemma in determining appropriate care for a severely ill patient, they were able to better understand and respect the patient's convictions and treatment choices due to this partnership with Jehovah's Witness leaders. Engaging faith leaders at these high stress times, as well as earlier in the process of advance care planning, addressed the patients' broader social, emotional, and spiritual needs in the context of their health care.

In 2002, CHCD produced its first Partners in Caring seminar for faith leaders in Sacramento on end-of-life care. This program, which helps bridge medical and ethical concepts with the spiritual aspects of care at life's end, has become an annual event. Targeted to leaders of religious institutions of all faiths, faith community nurses, health ministers, and other faith community leaders, the seminar includes local physicians, nurses, social workers, and faith leaders as faculty. In 2013, CHCD helped CCCC adapt this curriculum for use by other communities.

Coalitions have invited faith leaders to serve on committees to include their expertise and input in planning end-of-life outreach in the community. In 2013, the Journey Project in Sonoma County piloted CCCC's Partners in Caring Faith Training, which involved nearly two dozen participants from a variety of faiths. Evaluations were positive, and participants indicated that they felt empowered by what they learned and could apply it in their work. On her evaluation form, one parish nurse who participated in the training wrote: "The seminar was extremely enlightening. I had difficulty filling out the forms and thinking about my own death. Now I feel more at peace."

Involving faith leaders at the decisionmaking table demonstrated to other community stakeholders and consumers that the health care system was taking a holistic approach to end-of-life care. One interviewee shared:

“We are getting church leaders’ suggestions and guidance on how to do the messaging so that it’s very much a dialogue, a two-way street, instead of coming in from the outside as the ‘expert’ with information. Together we can come up with the best way to address the issue with their community.”

— Julie Boudreau
Hospice of Santa Cruz County

Conducting Multilingual and Multicultural Outreach

Research shows that attitudes toward death and dying vary by race and ethnicity. For example, in a 2011 survey, a greater percentage of Latinos (56% of surveyed) ranked “living as long as possible” as a priority, compared to the total population (36%).¹³

While some coalitions have made in-roads in reaching ethnic populations in their region, more needs to be done to better understand and address the specific cultural issues in these communities. As a basic starting point, information needs to be translated into multiple languages, and providers need adequate training in cultural competency.

Coalitions tailored their approach to end-of-life issues when working in different ethnic communities. In Santa Cruz and Sonoma Counties, for example, advance care planning advocates found that Latino community members have a more family-based decisionmaking process than the general population. Engaging faith leaders and telling personal stories about related experiences have been effective strategies with Latino patients. Several coalition members with experience working with the Latino community emphasized the importance of involving family members in advance care planning conversations and of meeting in people’s homes, as opposed to in a doctor’s office or at a hospital or clinic.

In discussing their experiences working with Chinese American patients and family members, coalition members discussed how members of this community respect expert advice, such as from a physician.

Reaching the Latino Community in Sonoma County

The Journey Project’s end-of-life initiative in Sonoma County conducted a workshop for Latino caregivers called “Wellness Through Life’s End: Planning and Navigating the Journey” four times between 2004 and 2010. Teresa Fernandez, a native of Mexico who works for a local hospice, volunteered to help with the development and teaching of the workshops in Spanish because she noticed that information about end-of-life services and options was not reaching the Latino community.

Fernandez explained how the content of the workshop resonated with Latino community values of keeping ill loved ones at home:

“[Latino] people think hospice is a place you take your elders because you don’t want them anymore.... By knowing this information, we realized our loved ones don’t have to die in a hospital or skilled nursing facility because there is help for them to die at home and to make decisions for themselves.”

A Spanish-speaking caregiver attended one of the workshops with a client’s needs in mind, but in the process learned about options for her own 90-year-old mother, who could no longer make health care decisions for herself. This caregiver’s family members had been told that a skilled nursing facility was the only option for her mother, but the family wished to keep her at home. Through the workshop, the caregiver learned about other palliative care options that allowed her mother to stay at home with family.

Strategies and Tactics for Successful Coalitions

Communities establishing new advance care planning initiatives should consider the following strategies and tactics used by the featured coalitions:

Overall Approach

- ▶ Target both providers and consumers to raise awareness within the health care system and the community at large.
- ▶ Combine promotion of advance directives and the POLST model as they complement, but do not replace, one another.

Establishing Leadership

- ▶ Map community stakeholders before defining coalition leadership to understand who is already championing advance care planning locally.
- ▶ Engage faith-based and other community leaders outside the health care system to address broader emotional and spiritual issues raised at end of life.
- ▶ Engage and use the experience of social workers and case workers who already address advance care planning to build on existing expertise and championship.
- ▶ Identify a physician champion for POLST who is passionate about improving end-of-life care and prominent in the medical community to establish credibility and build understanding about POLST in the health care system.

Training and Education

- ▶ Organize ethics discussion groups to create venues for providers to share experiences, best practices, and lessons learned.

- ▶ Encourage provider participation by holding meetings during lunchtime and evening hours to protect busy workday schedules.
- ▶ Incorporate training into residency programs, CME certification, and employee orientation to build a health care workforce skilled in end-of-life issues. In particular, equip providers with conversation skills to discuss end-of-life issues and promote familiarity with the various medical forms.

Outreach

- ▶ Hold meetings and distribute information at community centers and other locations where community members congregate.
- ▶ Develop and expand multicultural and multilingual initiatives by translating collateral materials and tailoring messages to reach ethnic communities that have specific cultural beliefs about dying.
- ▶ Take advantage of National Health Care Decisions Day (April 16) to raise awareness and provide community members with opportunities to access and complete advance directives. For example, set up tables at health care facilities and community centers and contact the media to garner attention for events.
- ▶ Develop and use a mailing list to reach consumers with information about workshops, events, and other advance care planning resources.
- ▶ Establish a staffed phone information line for consumers to call with questions.

Challenges

The coalitions addressed common challenges in their advance care planning initiatives:

- ▶ High turnover among health care providers results in new staff members who are unfamiliar with advance care planning and lack the skills to have meaningful end-of-life conversations.
- ▶ Providers lack the time to actively participate in coalitions that are largely volunteer-driven.
- ▶ Coalitions lack the funding to increase their own capacity, for example, to hire staff, organize workshops, conduct outreach, or expand programs.

- ▶ Fewer physicians attend coalition meetings compared with other care providers.
- ▶ POLST is perceived as too clinician-centric among some coalition members who had been engaged in advance care planning long before the POLST coalitions were established.
- ▶ Taboos and attitudes about death and dying foster an avoidance culture, making it difficult to have end-of-life conversations.

In addition to the challenges listed, many organizations were pursuing this work at a time when the health care industry was more focused on profit-driven high-tech

solutions to medical problems than on the low-tech conversations and community engagement efforts involved with advance care planning.

Future Directions

As California's advance care planning and POLST work have matured, community stakeholders have explored new ways to improve these efforts. Interest and awareness among the public have progressed to a new phase, with more regular media attention and national efforts. For instance, The Conversation Project, founded in 2010 by Pulitzer prize-winning journalist Ellen Goodman and a group of concerned media, clergy, and medical professionals, is helping people discuss their wishes for end-of-life care. It is not focused on the completion of medical forms, but on stimulating conversations about end-of-life care "at the kitchen table" between loved ones.

These California advance care planning coalitions have implemented a robust, grassroots, collaborative approach and engaged the broader community outside of the health care arena in the dialogue.

Expanding Outreach and Services

Coalitions are pursuing new and ongoing approaches to reach a broad swath of the community. Initiatives to expand outreach and services include:

- ▶ Continuing to engage and prepare faith leaders to involve key stakeholders outside of the health care system.
- ▶ Incorporating advance care planning into employee wellness programs.
- ▶ Using social media and other venues to reach young adults, especially young parents, to encourage them to complete advance directives and engage them in the conversation needed with older loved ones.
- ▶ Creating materials in more languages and for lower literacy levels.
- ▶ Expanding education of nursing home staff who play a key role in POLST education and completion.

Health Care Reform

Health care reform, and the payment reforms associated with it, have raised awareness and interest in palliative care and advance care planning. When palliative care consultation occurs, treatments that are not wanted by patients can be avoided, with resulting reductions in health care costs.¹⁴ Coalition members noted that frail patients often need social services more than medical services. Palliative care involves a team approach including social support services that address these needs and are typically less costly than medical treatment.¹⁵⁻¹⁷ Health care systems are recognizing the importance of palliative care and advance care planning in addressing the "triple aim" of improving care, improving the patient experience, and lowering costs.

"I think we all realize that we need . . . to give the right type of care at the right time at the right place. This is a fabulous thing. . . . I think health care reform is bringing palliative care more into the picture."

— Dr. Tarek Mahdi
Inland Empire Palliative Care Coalition

County-Supported Initiatives

In 2013, the Committee for Healthcare Improvement in Sonoma County, a coalition of local health system stakeholders, launched a community-based Advance Care Planning Community Initiative to raise awareness about the need to have end-of-life conversations among patients, family members, and health care providers, and to promote the use of advance directives throughout Sonoma County. The initiative is connected to the goals of Sonoma Health Action, a countywide, multi-sector council supported by the Sonoma County Department of Health Services working to improve the County's overall health. The vision of Sonoma County's Advance Care Planning Community Initiative is for every person in the county to become educated and empowered to express his/her wishes about end-of-life care, to have the opportunity to do so, and to have his/her wishes honored. Such countywide initiatives involving local government agencies will be examples to watch for potential replication.

Improving Documentation

Making forms and information portable is a pressing need across the health care industry. Because patients may change health plans, move, and see a range of different care providers that are not part of the same group, it is important to develop an electronically accessible registry of POLST and advance directive forms. Health information technology should be harnessed to track end-of-life documents to ensure that they can be accessed when needed.

For example, patients who arrive at an emergency department in the middle of the night may not be seen by their regular provider. If an electronic version of their POLST and advance directives forms were available, the emergency department providers would know what the patients' care plans and wishes were and could act accordingly.

Need for More Data and Research

There is a great need for more data and research on a variety of aspects of advance care planning. For example, data on the prevalence of advance directives is limited. While one national survey found that 26% of respondents had advance directives, there is no ongoing data collection effort, nationally or statewide.¹⁸ Having better data would provide benchmarks and help establish targets for improvement. Similarly, little data exists on health outcomes resulting from advance care planning programs.

Much is still not well-understood about what comprises a good conversation about end of life among the different players (patients, family members, and health care providers), in different settings, and with different populations (for example, different age groups and different ethnic groups). This research would help facilitate the spread of advance care planning programs.

Let's Get Healthy California Task Force Targets End-of-Life Issues

In 2012, California Governor Jerry Brown established the Let's Get Healthy California Task Force to "develop a 10-year plan for improving the health of Californians, controlling health care costs, promoting personal responsibility for individual health, and advancing health equity."¹⁹ Demonstrating the shift in focus toward advance care planning, one of the six goals identified by the Task Force was "End of Life: Maintaining Dignity and Independence." The priorities of this end-of-life goal are to:

- ▶ Decrease hospitalization during the end of life
- ▶ Increase the use of palliative care and hospice care
- ▶ Increase completion of advance directives

The Task Force noted that measures to monitor patient preferences for care and processes for documenting and complying with these wishes are needed and critical to the success of this initiative.

Conclusion

Opportunities abound for expanding and improving advance care planning. Communities establishing new advance care planning initiatives, both in California and around the United States, can use the strategies of the successful coalitions outlined in this paper.

Central to these coalitions' success was a grassroots, collaborative approach in which leadership and ownership was shared across organizations in the health care system. Their strategies also involved targeting both providers and consumers, and outreach and education that incorporated different aspects of advance care planning: the POLST form, advance directives, palliative care, and end-of-life conversation skills.

With advances in health care reform and greater public awareness about end-of-life issues, supporting artful conversation between providers, patients, and family members about advance care planning can become the standard of care.

Appendix A: Interviewees and Contributors

Interviewees

Julie Boudreau
Education and Outreach Program Manager
Hospice of Santa Cruz County

Judy Citko, JD
Executive Director
Coalition for Compassionate Care of California

Teresa Fernandez
Latino Program Co-Director
Community Network Journey Project

Marge Ginsburg
Executive Director
Center for Healthcare Decisions

Kathy Glasmire
Associate Director
Center for Healthcare Decisions

Lori Houston
Program Planning and Evaluation Analyst
County of Sonoma Department of Health Services

Susan Keller, MA
Executive Director
Community Network for Appropriate Technologies
Community Network Journey Project

Eleanor Littman, MSN
Executive Director
Health Improvement Partnership of Santa Cruz County

Tarek Madhi, MD
President, Riverside County Medical Association
Chair, Inland Empire Palliative Care Coalition

Natalie Moy, LCSW
Director, Patient Care Management
Riverside County Regional Medical Center

Contributors

Leilani Ann Maxera, MPH
POLST Program Director
Coalition for Compassionate Care of California

Susan Tolle, MD
Director, Center for Ethics in Health Care
Oregon Health and Science University

Appendix B: Coalition Membership

Over the years since these POLST coalitions were formed, membership may have changed. These lists reflect coalition membership as of the indicated date.

Riverside/San Bernardino Coalition*

(as of March 2014)

All Care Home Health
AmeriHealth
Arrowhead Regional Medical Center
At Home Respite Care
Brandman University
Care Alternatives Hospice
Care of Southern California
Charter Healthcare
City of Hope
Companion Hospice
Corona Regional Medical Center
Destiny Hospice Care, Inc.
Family Hospice Care
Gentiva Hospice
Hope Hospice and Healthcare
Kaiser Permanente Fontana Palliative Medicine
Kaiser Permanente Medical Center – Fontana
Kaiser Permanente Riverside
Loma Linda University Medical Center
Parkview Community Hospital
Reliance Hospice
Respite Care Home Care
Riverside County Regional Medical Center
Riverside Emergency Medical Services
Seasons Hospice and Palliative Care
St. Bernardine Medical Center
Temecula Valley Hospital
Visiting Nursing Association California
Visiting Nursing Association Hospice & Palliative
Vitas Innovative Hospice Care

Sacramento Area Coalition†

(as of March 2014)

Deon Batchelder
Professional Geriatric Care Manager
Elder Options
Melissa Borrelli, JD
Local Attorney
Christine Evans, RN, MSN
Clinical Educator
Dignity Health Strategic Learning Development
Kathy Glasmire
Associate Director
Center for Healthcare Decisions
Paul Janke, DMin
Retired Area Director
Lutheran Social Services Northern California
Candy Kodama, RN, MA
Hospice Facility Care Coordinator
Mercy Hospice
Catherine McGregor, RN, MSN
Nurse Coordinator, Palliative Care Program
Sutter Auburn Faith Hospital
Jan Van der Mei, RN
Regional Ambulatory Care Management Director
Sutter Health Sacramento Sierra Region

Santa Cruz County Coalition*

(as of November 2009)

Aegis Assisted Living
Central California Alliance for Health
Dominican Hospital
Driftwood Medical Center
Elderday Adult Day Health Care Center
End of Life Coalition of Santa Cruz County
Health Improvement Partnership of Santa Cruz County
Heartland Hospice
Hospice of Santa Cruz County

Kindred Santa Cruz Healthcare Center
Lifespan Care Management
Oak Tree Villa Senior Living
Palo Alto Medical Foundation
Santa Cruz County Emergency Medical Services
Watsonville Community Hospital

Sonoma County POLST Coalition[†]
(as of March 2014)

Nina Arbour
Hospice Community Educator and Volunteer
Coordinator, St. Joseph Health

Brian Arendt
Community Liaison
Heartland Hospice

Pam Campbell, MPA
Project Manager
Inquiring Systems

Terri Dente
Area Director, Mission Integration
St. Joseph Health

Teresa Fernandez
Latino Program Co-Director
Community Network Journey Project

Tim Gieseke, MD
Internist
Elder Care Practice

Judith Goleman, MFT
Rabbinic Pastor
Marriage and Family Counselor

Gary Johanson, MD
Palliative Care and Hospice Specialist

Susan Keller, MA
Executive Director
Community Network for Appropriate Technologies

Annette Lille
Chaplain
Santa Rosa Memorial Hospital

Frank Mueller, MD
Palliative Care and Hospice Specialist

Brian Pflaucher
Chaplain, Heartland Hospice
Assistant Minister, Community Church of Sebastopol

Paula Shatkin, LCSW
Case Manager
Palm Drive Hospital

Reverend Sally Singingtree, MA
Chaplain/Interfaith Spiritual Care Provider

Eloise Tweeten
Founder
Tweeten Elder Care Advisors

Andrew Wagner, MD
Integrative Medicine
Hospice, and Palliative Care Specialist

Reverend Kimberly Willis
Residency Chaplain
Alta Bates Summit Hospital

*Coalition is comprised of participating organizations.

†Coalition is comprised of individuals volunteering their time independent of their organizational affiliation.

Endnotes

1. California HealthCare Foundation, *Final Chapter: Californians' Attitudes & Experiences with Death & Dying*, February 2012, www.chcf.org.
2. Ibid.
3. PBS, www.pbs.org, accessed March 12, 2014.
4. POLST national state listing, www.polst.org/programs-in-your-state, accessed March 12, 2014.
5. California Coalition for Compassionate Care, www.coalitionccc.org/who-we-are/local-coalitions, accessed February 17, 2014.
6. National Institute on Aging, Advance Care Planning, www.nia.nih.gov/health/publication/advance-care-planning, accessed March 19, 2014.
7. National Institute of Health Medline Plus, Advance Directives, www.nlm.nih.gov/medlineplus/advancedirectives, accessed March 11, 2014.
8. National Institute on Aging, Advance Care Planning, www.nia.nih.gov/health/publication/advance-care-planning, accessed March 11, 2014.
9. National Institute of Health Medline Plus, End of Life Issues, www.nlm.nih.gov/medlineplus/endoflifeissues, accessed March 11, 2014.
10. National Institute of Health Medline Plus, Hospice Care, www.nlm.nih.gov/medlineplus/hospicecare, accessed March 11, 2014.
11. National Institute of Health Medline Plus, Palliative Care, www.nlm.nih.gov/medlineplus/palliativecare, accessed March 11, 2014.
12. Definition jointly developed by the California HealthCare Foundation and the Coalition for Compassionate Care of California.
13. California HealthCare Foundation, *Final Chapter: Californians' Attitudes & Experiences with Death & Dying*, February 2012, www.chcf.org.
14. Morrison RS et al., "Cost Savings Associated with US Hospital Palliative Care Consultation Programs," *Archives of Internal Medicine*, 2008;168 (16), 1,783–1,790.
15. American Academy of Hospice and Palliative Medicine, What Is Palliative Care?, www.palliativedoctors.org/about/team, accessed April 2, 2014.
16. Bradley EH et al., "Health and Social Services Expenditures: Associations with Health Outcomes," *British Medical Journal* (October 2011) 20 (10): 826–831.
17. Thomas KS and Mor V, "Providing More Home-Delivered Meals Is One Way To Keep Older Adults with Low Care Needs Out of Nursing Homes," *Health Affairs* (October 2013) 32(10): 1,796–1,802.
18. Rao JK et al., "Completion of Advance Directives Among US Consumers," *American Journal of Preventive Medicine* (December 2013) 46(1): 65–70.
19. California Department of Health and Human Services, *Let's Get Healthy California Task Force Final Report*, December 2012, www.cdph.ca.gov.