

California Health Care Foundation



Finding Focus: Reflections on a Decade of Work in End-of-Life Care

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About the Foundation

The California Health Care Foundation is dedicated to advancing meaningful, measurable improvements in the way the health care delivery system provides care to the people of California, particularly those with low incomes and 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.

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The contradictions were evident, the needs clear.

n 2006, the California Health Care Foundation (CHCF) issued its report *Death and Dying in California*, which highlighted the contradictory finding that while most people express a desire to conclude their lives in the comfort and familiarity of their home, 70% will die in a hospital or nursing facility. And while 83% regard end-of-life wishes to be important for themselves and their families, only 36% have committed their preferences to writing. Two years later, only 43% of the state's hospitals offered such services, with public hospitals, which serve predominantly low-income patients, hitting a scant 24%.

How should CHCF respond to such stark contradictions? And how could a single foundation use its limited resources to move the nation's largest state — with one of the most diverse populations — toward significantly improved policies, planning, and actions in regard to serious illnesses and end-of-life care?

CHCF began by narrowing its focus. Rather than launch a diverse portfolio of indeterminate efficacy and then sorting over time among the winners and losers a common approach throughout philanthropy — the foundation opted for a single goal bolstered by two prime strategies.

In 2007, CHCF announced its intention to "promote appropriate care toward the end of life by eliciting and honoring patients' wishes." To make measurable advances over the course of a decade, the foundation would develop an expanding roster of grants to (1) promote the awareness and adoption of POLST (Physician Orders for Life-Sustaining Treatment) and (2) support sustainable palliative care programs, starting with California safety-net hospitals.

"We wanted to elicit people's wishes in regard to the end of their lives," said Kate O'Malley, CHCF's senior program officer, who led the efforts for 10 years, until her retirement in 2017, "and then work with the health system to make those wishes possible. But we have finite resources, time, and leverage. Sometimes, our grants started small and ended up having a national impact. But small or large, we were looking for a return on investment." Over the course of a decade, CHCF's grantmaking portfolio developed organically, responding to persistent needs and sudden opportunities as it simultaneously worked multiple levers among policymakers, consumers, clinicians, and insurers. The foundation assembled a mosaic of services and interventions that proved mutually reinforcing, branching out over time while consistently bolstering the main goals and prime strategies. To participants and informed observers throughout the state and across the country, this approach proved highly successful, worthy of consideration by funders aspiring to make a comparable impact in their own regions.

Starting Out with POLST

The program's first major investment focused on the adoption and spread of POLST, starting in 2007 with a set of modest grants that over time galvanized interest across the state.

POLST is a paradigm for eliciting and documenting patient wishes: It starts with frank and detailed conversations between medical providers and their seriously ill patients about prognosis, treatment options, and the patient's personal desires and values. These conversations result in a standardized medical order, signed by the patient and provider, indicating the specific types of life-sustaining treatment that the patient does and does not want. Printed on eye-catching bright pink paper, the POLST form travels with the patient throughout stages and settings of care — a concise, vivid, and considered summary of treatment preferences.

CHCF made its lead POLST grant to the Coalition for Compassionate Care of California (CCCC), the foundation's partner in formulating a strategy for introducing POLST statewide. With the goal of bringing together thinkers and activists in the health care system, government, consumer organizations, and the general public, CCCC proved the ideal partner.

"Our collaboration began with thinking together about whether this area was right for funding and what it might look like," said Judy Thomas, JD, the CEO of CCCC. "We jointly put together the proposal. We knew we had to take both a top-down and a bottom-up approach because we're such a big state." The strategy called for the formation of a statewide task force composed of consumers, health care providers, advocates, and state regulators. Newly established community coalitions recruited local representatives from hospitals, nursing homes, and emergency medical services (EMS). While Oregon's successful 20-year-old program offered a model for implementing the POLST paradigm, the organizers strove to tailor the fledgling operation to the varied needs of California's large and diverse population.

"Building a coalition [around POLST] with [California's] huge diversity of stakeholders was a big challenge," said James Mittelberger, MD, MPH, who served as chair of the California POLST Task Force. "Many small grants formed the basis around which people could meet. Most people were working without compensation. The grants gave a bit of funding to pull together a meeting room, maybe a meal. They had a remarkable magnified impact." Multiple convenings spurred on practical refinements of the new POLST form. "We had many ongoing modifications to make sure everybody's concerns were addressed. For example, working with emergency medical services, we knew we had to have something that fit their processes around the clock, 365 days a year."

In communities where local champions were already devoting time and energy to improving end-of-life care, POLST advocates found natural allies. In other regions, new coalitions formed — ultimately numbering 27 statewide. Aided by small organizing grants, local activism flourished.

"Leaders emerged to champion POLST in their communities," said Thomas. "We made sure they got accurate information and training. We ran interference when problems arose" — such as nursing homes mailing POLST forms to family members to fill out without the doctorpatient consult, or other institutions trying to make POLST mandatory despite its voluntary status.

While the bottom-up community organizing effort grew, advocates lobbied the state legislature to secure a policy foothold. In 2009, the passage of AB 3000 codified the form and use of POLST in California, and guaranteed that it would be honored across all settings of care without providers fearing liability.

With policy secured and consumers engaged, the initiative deepened its commitment to workforce development.

CCCC developed a host of materials, including online resources, quick reference guides for physicians and nursing home facilities, daylong workshops on conducting compassionate POLST conversations, a related video illuminated by vignettes conveying eight personal stories of doctor-patient interactions along with a companion discussion guide, and a two-day train-the-trainer curriculum to expand the conversational comfort and capacity of doctors and other health care professionals. To date, more than 1,000 individuals have used the trainer's curriculum.

"We have to constantly remind people that it's all about the conversation," said Mittelberger. "Challenges arise when forms are completed without a high-quality conversation. But with POLST and supporting materials, we now have a set of tools that aid all of us. I've seen many families reassured that their choices are clearly stated. That includes both people who want very aggressive care and those who want selective care."

"We have to constantly remind people that it's all about the conversation."

— James Mittelberger, MD, MPH

By 2012, 95% of California nursing homes had at least one resident with a completed POLST form, 65% of hospitals had adopted a formal POLST policy, and 75% of assisted living facilities had conducted POLST education for staff. Key to the initiative's success has been the reliance on feedback loops that allow for the revision of materials and the persistent tweaking of promotional methods.

As POLST became widely used throughout the state, CHCF conducted a series of interviews with 10 coalitions in four counties, highlighting the practices that enabled advance care planning to take root locally. A broader survey conducted in 2014 by Neil Wenger, MD, MPH, director of the UCLA Health Ethics Center, detailed "What We Know About POLST in California" among nursing homes, hospitals, EMS providers, and POLST community coalitions. A key finding pointed to challenges in completing a POLST form and guaranteeing its portability with the patient. The study advocated use of an electronic registry for POLST, a practice already adopted by four other states — including Oregon, where multiple studies have shown concordance between treatment and preferences documented in POLST forms. In 2015, the California State Senate authorized the pilot test of a POLST electronic registry, followed shortly by CHCF funding to support the pilot, a first step toward learning what it would take to implement a permanent statewide registry.

Palliative Care in California's Safety-Net Hospitals

A similar approach to making strategic interventions in the health system — and then taking the measure of changes and crafting appropriate adjustments — has guided CHCF's involvement in the complex task of improving palliative care throughout California. Again, the foundation based its first steps on data, and directed its initial efforts toward the state's safety-net hospitals.

Public hospitals in California serve 2.5 million patients annually, many of whom arrive for care at the late stages of their illness. Yet in 2007 only 24% of the state's public hospitals — four of 17 offered palliative care programs.

Public hospitals in California serve 2.5 million patients annually, many of whom arrive for care at the late stages of their illness. Yet in 2007 only 24% of the state's public hospitals — four of 17 — offered palliative care programs. To reach the patients most in need (and whose delayed treatment invariably drives up health care costs), CHCF launched a five-year initiative called Spreading Palliative Care in Public Hospitals (SPCPH). By the end of 2012, 100% of California's public hospitals had assembled their clinical teams — a physician, nurse, social worker, and/ or chaplain — and were offering inpatient palliative care.

"With each hospital seeing 250 to 300 patients," said Steven Pantilat, MD, professor of medicine and founding director of the UCSF Palliative Care Program, "we're talking about thousands of people each year." Once the grants ended, the hospitals assumed financial support for their palliative care teams — persuaded by the teams' business case analyses, which demonstrated both improved patient care and reduced costs. "As a result, tens of thousands of individuals have benefited since the project began."

From the beginning, SPCPH employed the collaborative spirit that led to the success of the CHCF POLST Initiative. In 2008, CHCF formed a partnership with the California Health Care Safety Net Institute, an organization allied with the state's public hospitals to improve care, and UCSF's Palliative Care Leadership Center. The collaborative hired a project manager, contracted with a former hospital administrator versed in the complications of public funding, and invited all 17 public hospitals with county contracts for indigent care to convene, discuss the appropriate steps forward, and then apply to CHCF for a \$25,000-\$30,000 planning grant.

The planning grants afforded each institution an opportunity to spend up to six months surveying its particular needs, framing approaches to new or amplified services, budgeting costs, and securing the commitment of hospital executives. SPCPH initiative faculty encouraged creative approaches to research: One applicant organization journeyed to Illinois's Cook County public hospital to observe its team working with a large, linguistically diverse, low-income urban population.

The four California public hospitals with existing palliative care programs then applied to CHCF for expansion grants. One, for example, dedicated funds to hiring a bilingual social worker to assist Spanish-speaking patients during the evenings and on weekends. The newcomers to palliative care applied for implementation grants, with monies dispatched over the course of three rounds to assure an orderly rollout and copious oversight.

"Part of our work," said CHCF's O'Malley, "was helping each grantee develop the business case. We wanted to make sure they could go to their chief executive officer and say, 'If we see people with serious illness earlier on, they will not use the ER to manage their disease, not have a terminal admission to the hospital, and not die in ICU.' Over the course of the project, we learned the language to help teams present a compelling case using data available in their own hospitals."

Branching Out and Making Connections

As grantmaking expanded and diversified, the foundation began to analyze the results through the prism of six action areas aimed at one critical outcome: measurable impact. Grants were sorted into the program "levers" or effective tools for change: (1) policy, (2) consumer engagement, (3) workforce development, (4) payment and purchaser requirements, (5) data and transparency, and (6) effective interventions. While this framework was helpful with philanthropic design and follow-up, in the real world the levers were interconnected, with actions in one area proving mutually informative and reinforcing to another. In the end, the foundation's impact on palliative care and end-of-life issues proved more powerful than the sum of its discrete grants.

"The foundation has been an exemplar for how philanthropy can invest in and effect the fundamental transformation of the health care system," said Diane Meier, MD, director of the Center to Advance Palliative Care and the recipient of a 2008 MacArthur Fellowship. "It has analyzed the various levers necessary to improve access, including lack of payment, lack of training, lack of capacity in hospitals and community settings. It's invested in all of those domains. Put it together, you can see the needle moving on palliative care in California. I wish every state had a foundation that was as strategic and clearheaded about what's necessary to change the health care system."

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Technical assistance has helped grantees address common problems. Anne Kinderman, MD, director of the Supportive & Palliative Care Service at Zuckerberg San Francisco General Hospital and Trauma Center said, "At our monthly conference calls, a number of us were usually struggling with the same issues, and we talked about our own ways of addressing them. It built a community. I'd have email addresses, contact info, and some acquaintance with my peers. Then later, if I had a patient who wanted to spend time with family in Los Angeles during the final weeks of life, I knew who to call to link that person up with appropriate care in the new location."

Unlike some philanthropic relationships that begin by issuing a check, conclude with a final report, and offer meager contact in between, the relationship between the foundation and project leaders steadily grew and intensified over time.

"Site visits were powerful," said Kinderman. "In my experience, it's unique to have a funder meet with the hospital administration. The foundation could highlight our work to our executive in ways that would have been difficult for us, and then clarify the commitment needed on our end to move forward with additional funding."

Staffing Palliative Care

Expanding palliative care throughout California's public hospitals — and beyond — also shed light on numerous gaps in the health system that required attention. Clinical staffing needs were among the most pressing issues.

"We don't have enough palliative care-trained doctors, nurses, social workers, and chaplains to staff our teams," said Pantilat. "We train four doctors a year to be palliative care specialists at UCSF — about 20 in the entire state. We need training fellowships for nurses, too. There are one or two internships for social workers, but they also need dedicated training. Beyond specialization, it's important to make sure that every doctor, nurse, social worker, and chaplain understands palliative care basics. Most people won't need specialty palliative care. But they need their doctors, and everybody else, to know enough to treat their pain, talk about their wishes, and address their psychospiritual issues."

CHCF has worked to address these staff shortages through support of the Institute for Palliative Care (IPC) at California State University San Marcos.

"We're a health care workforce development engine," said Helen McNeal, executive director of the institute, speaking of the entire CSU system's 460,000 students at 23 campuses producing 15% of the nation's graduates in allied health fields. Founded in 2012, the San Marcos campus's IPC offers symposiums, workshops, and 46 online courses designed for the full range of health professionals working in primary and specialized care. To date, the IPC has trained more than 3,600 individuals. Most recently, dedicated cohorts of nurses have enrolled in a nine-month program resulting in an advanced practice RN certificate, a model that could be replicated by other professions.

As palliative care expanded throughout the state's public hospitals, practitioners saw the need to train on-site interpreters. A 2010 survey revealed that 35% of patients receiving palliative care in California's public hospitals spoke limited English. Since palliative care relies on clear communication among team members, patients, and families, interpreters had to acquire a fundamental grounding in aims and methods — along with assistance in negotiating a disparate range of cultural attitudes toward illness and death. Interpreters also had to cope with their own feelings about mortality. To this end, the foundation funded the development of a seven-hour workshop curriculum for the trainers of health care interpreters — the course free, downloadable, and available in the seven languages other than English most frequently spoken in public hospital settings.

"Interpreting is a difficult job," acknowledged O'Malley. "One minute, you're in a well-baby clinic helping families understand the reasons for their infants' inoculations, and then next, you're at a patient's bedside for an end-of-life conversation."

Staffing shortages remain challenging, and most observers agree that an adequate level of broadly dispersed expertise will take many years to achieve. But over the past decade, the attention and funding directed at the full cadre of health professionals has had the salutary effect of weaving the ethos and practice of palliative care into many primary care settings — a long-term goal whose realization can be vividly witnessed today.

"What brings me no end of joy," said Kinderman, "is when regular providers at the hospital make it clear that they expect a higher standard of care when people are approaching the end of life. Nurses caring for people in the last days or hours know how it can go. If the patient isn't getting good care, they call us. They tell us that we need to help, that the current care is not acceptable. We had an occupational therapist last week who was seeing a cancer patient with an infection in his arm. The therapist advocated with the orthopedic surgeon to get more support for the patient's cancer. That happens now with the social workers, nutritionists, speech therapists, and other medical services."

Financing the Future of Palliative Care

As palliative care spreads throughout the state's public and private hospitals, increased attention has also turned to the need for sustainable financing by forging payerprovider partnerships.

"These partnerships are hard," said Michael Rabow, MD, director of the Symptom Management Service at the UCSF Helen Diller Family Comprehensive Cancer Center and associate director of the UCSF Palliative Care Leadership Center. "There are many people involved in lots of relationships, and it's not clear yet what needs to come of all this. But the future of palliative care, like most health care, is going to be about the relationships between payers and providers. It's the leading edge."

In 2014, CHCF awarded planning grants to 10 teams of providers and payers to lay the groundwork for agreements that would provide community-based palliative care services outside the hospital and prior to enrollment in hospice. These planning grants led to implementation support from CHCF for six of the teams, thereby launching a set of innovative strategies for handling the persistently challenging task of palliative care financing.

"Collaborative work reveals both the stress points and the benefits."

— Kate O'Malley, senior program officer California Health Care Foundation

"Collaborative work reveals both the stress points and the benefits," said O'Malley. "It's unusual for payers and providers to work together over one to two years to create finance, metric, and service structures and not see themselves in opposition. Usually, the payer doesn't feel they'll get the service they want from the provider, and the provider feels the payer is always aiming for the lowest prices and never fully paying for their services. In our collaborative, both sides came up with solutions. They strove to target the right people with the right level of service and then use the right metrics to show both the savings and the good health results. In the end, they recognized that palliative care reduces cost and improves outcomes, and they ended up caring about their partnership."

Today the participants in the implementation grants are looking for ways to build on their work, both by addressing challenges in their current partnerships and by seeking additional partners to expand their reach. While nobody would suggest that the complications of palliative care's insurance-based financing have been resolved, the good-faith, imaginative hard work of all parties indicates the possibility of myriad improvements in an area where many observers had in the past perceived only barriers.

Responding to Grantmaking Opportunities

Expanding the borders of possibility has been an aim of much CHCF grantmaking, large and small, in this area of work. And over time, with an array of major projects flourishing, unforeseen opportunities began to appear.

A modest \$5,000 grant to the Institute for Poetic Medicine enabled the palliative care teams at UCSF to find their voice in poetry and express the intense, complicated feelings that accompany their work. To build expertise in the field of palliative care during its nascent stages, the foundation underwrote a series of 42 papers published over seven years in JAMA: The Journal of the American Medical Association and later offered as a book, Care at the Close of Life: Evidence and Experience — a landmark guide inspiring further contributions in theory and practice.

The foundation also demonstrated how nimbleness and a degree of risk-taking could advance long-term goals through the rapid response to sudden changes on the ground. In 2015, PBS's *FRONTLINE* aired a film adaptation of surgeon Atul Gawande's surprise best seller, *Being Mortal: Medicine and What Matters in the End.* An audience of 2.5 million viewers watched Gawande's moving chronicle of patients and their families at the end of life, including an intimate portrayal of the death of the author's father. While impressively large, the national audience also proved narrow. Two-thirds of viewers had attended college, and 84% were white. CHCF teamed up with the documentary's funder, the John and Wauna Harman Foundation, to promote screenings within Asian American, African American, and Latino communities, with the film followed by a guided discussion about end-of-life choices. Enthusiasm for the project exceeded initial expectations. The original plan for 25 grants grew to accommodate 39 organizations. Sixty-five screenings sponsored by churches, senior groups, medical care networks, and end-of-life coalitions drew more than 3,000 community members.

"It's all about cultural change," said Elyse Salend, MSW, program officer with the Cambia Health Foundation. "CHCF was big enough to plant seeds and bring about cultural change that couldn't have been accomplished by smaller foundations. Timing was key. I saw Gawande's book for sale in Costco. Friends of mine who never talked to me before about my work in palliative care asked me what I thought about it. There's more public conversation now. The pendulum has shifted. When I go to a national meeting, I encounter at least 3,000 people who are passionate and dedicated. They're going to lead and train others — the generalist, the receptionist, the CMA [certified medical assistant]."

"It's all about cultural change."

- Elyse Salend, MSW, program officer Cambia Health Foundation

Some aspects of cultural change can prove exceedingly difficult to anticipate. While *Being Mortal* evidenced the literary (and subsequently, cinematic) virtues of vivid storytelling, narrative clarity, and a strong emotional thrust, much of the information provided by both the book and film had been accessible for many years. Yet Gawande's authoritative and personal story managed to spark unprecedented national interest. Being ready and willing to take advantage of popular culture's sudden shifts has certainly contributed to CHCF's impact. But as important has been the foundation's ongoing collaboration with the large, influential institutions of government that can shape public policy for millions of people over multiple decades. In recent years, CHCF has worked with health care leaders from both the public and private sectors to make certain that Let's Get Healthy California, the state's 10-year plan "to make California the healthiest state in the nation," included goals for advance care planning, increased hospice use, and access to hospital-based palliative care. The foundation also assisted advocates who crafted SB 1004, a groundbreaking piece of state legislation that requires the California Department of Health Care Services to ensure the delivery of palliative care to Medi-Cal (Medicaid) managed care patients.

"SB 1004 has something the rest of the country is very interested in," said Rabow. "It's instructive that the state came up with the regulation. CHCF and others are trying to realize its promise by figuring out how to turn this mandate into improved care, especially in institutions that are financially strapped."

"Foundations can spend all the money in the world," said Salend. "But government has a critical role with training, fellowships, even respite care for families." If government withdraws support, she believes, "foundations will never be able to compensate."

Government support — along with credibility among the health care establishment and the public - will increasingly depend on proof of palliative care's efficacy. In crucial ways, the benefits of palliative care have already been confirmed. Doctors and nurses involved in its regimen understand the clinical benefits; attentive hospital administrators perceive the cost savings; and patients and their families recognize the physical, emotional, and spiritual value of deploying resources so that seriously ill people may have the best life possible regardless of the ultimate direction of their treatment. But the means of providing palliative care in a variety of settings - the best practices, measurable outcomes, and institutional demands — will only emerge over time as the movement grows and the data and anecdotal evidence fall under close and persistent scrutiny.

"We need to understand what quality means. How to measure it, and then make improvements"

— Steven Pantilat, MD, professor of medicine Founding director, UCSF Palliative Care Program "We need to understand what quality means," said Pantilat. "How to measure it, and then make improvements. That's something we're now doing with CHCF and the Palliative Care Quality Network. We're collecting data on 88 palliative care teams treating 75,000 patients across the country." Once completed, the database will show which palliative care teams and approaches have achieved the best patient outcomes — a point of comparison that marks a crucial step toward describing the ideal state of the art.

"We're still codifying specialized palliative care," said Mittelberger. "It's a very young field. Even finding the patients that need the intervention can be a challenge. Who's really going to benefit? How do I identify the patients in need and get the right treatment to them at the right time?"

A Culture of Effective Philanthropy

CHCF's effectiveness over the past decade owes much to its clearly defined, achievable goals; its strategic approach; and the substantial size of its grants. But the foundation has also contributed to the field by communicating with grantees in a manner they describe as highly collaborative.

"CHCF recognized the critical truth that the process is the product," said Meier. "Funders can't just step into the fray and say what should happen. They have to fund the process that brings together the stakeholders to hammer out a consensus. That provides deep-rooted legitimacy across the state."

Longtime advocates speak of the "tremendous synergy" of shared projects, the value of mutual support, the importance of "sharing and comparing our data and experience." Yet another unexpected word frequently emerges when practitioners and advocates reflect on their years spent working together. "The first thing that comes to mind," said Rabow, "is the fun we had. Even though the work is hard, with lots of barriers, there was always a sense of, 'Well, we're all going to roll up our sleeves and try to do some good here, so we might as well have the best time we can.' Over the years, I heard Kate O'Malley open every single conference with that sentiment — a sense that we don't have to be too serious about doing this very important work. Kate never had too much invested in pursuing one idea or approach over another. I've heard her say many times, 'If it's not working, let's try something else.' Other people will work their preferences to the bitter end. It's refreshing to have a program officer who not only understands the field, but also gets the human side of the work."

Today the palliative care cohort also extends to funders. Conference calls scheduled every three months bring together experienced hands and novices, regional players and national foundations. Before the calls began, fewer than a half dozen funders were consistently supporting work with palliative care and end-of-life issues. Today more than 30 participate in the conference calls. Amy Berman, senior program officer with the John A. Hartford Foundation, facilitated the first call; CHCF's O'Malley handled the second.

"We don't own the collaborative," said Berman. "It belongs to whoever is participating. Our purpose is to be more strategic. We share what we're doing, see where the gaps are, and figure out where our interests intersect, so we can join together to form a patchwork of support for the field."

Meier sees potential for philanthropy to make further contributions to palliative care and extend the practice nationally as it achieves both breadth and depth. "They have to do their homework. Read widely. Speak to leaders in the field. Put together a broad perspective with a SWOT [strengths, weaknesses, opportunities, and threats] analysis. Invest where opportunities are most likely to yield a positive impact. Success has a tremendous amount to do with leadership," she emphasized. "... leadership that educates its board and its constituents about what are high-impact, high-bang-for-the-buck strategies."

And what will success ultimately look like?

"Everyone who takes care of patients with serious illness," said Kinderman, "will have sufficient training to provide a primary level of palliative care. They'll feel comfortable having conversations about prognosis and treatment options. They'll be aware that there are issues beyond their skill set, and they'll be able to refer to specialists in palliative care wherever patients are located — in a clinic, nursing home, hospital, or home."

"Getting to know my patients," said Pantilat, "having meaningful relationships and helping them to live their lives well — that's the essence of palliative care. The real challenge facing all of us is how to live well with a serious illness. The physical, emotional, social, spiritual challenges. How do we make sure people get care that helps more than it hurts, that's consistent with their values and goals. That lets them live as well as possible for as long as possible."

Milestones: CHCF's Work in End-of-Life Care

