

**End of Life Grantmaking in the United States:
A Review of Key Literature and Entities**

—

Prepared for the John and Wauna Harman Foundation

Christine Sherry
October 2015

TABLE OF CONTENTS

| | |
|---|--------|
| FUNDERS | 1 |
| Archstone Foundation | 2 |
| California HealthCare Foundation | 4 |
| Cambia Health Foundation | 6 |
| The Fan Fox and Leslie R. Samuels Foundation | 8 |
| Gordon and Betty Moore Foundation | 9 |
| Jewish Healthcare Foundation | 10 |
| John A. Hartford Foundation | 12 |
| The John and Wauna Harman Foundation | 13 |
| The Pew Charitable Trusts | 14 |
| Stupski Foundation | 15 |
| ORGANIZATIONS | 16 |
| ACP Decisions | 17 |
| Center for Practical Bioethics | 18 |
| Center to Advance Palliative Care | 21 |
| Coalition for Compassionate Care of California | 23 |
| Coalition to Transform Advanced Care | 26 |
| The Conversation Project | 28 |
| The Hastings Center | 31 |
| National Academy of Medicine | 33 |
| Lown Institute | 35 |
| MyDirectives.com | 37 |
| National Hospice and Palliative Care Organization | 38 |
| PREPARE for Your Care | 41 |
| The Wake Up to Dying Project | 42 |
| HISTORICAL FUNDERS | 43 |
| Robert Wood Johnson Foundation | 44 |
| Open Society Institute/Open Society Foundation | 46 |
| AFFINITY GROUPS | 49 |
| Grantmakers in Aging | 50 |
| Grantmakers in Health | 51 |

| | |
|--|--------|
| KEY LITERATURE | 52 |
| Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)..... | 53 |
| Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field..... | 55 |
| Transforming the Culture of Dying: The Project on Death in America, October 1994 to December 2003..... | 61 |
| The Dartmouth Atlas Project..... | 66 |
| <i>Being Mortal: Medicine and What Matters In the End</i> | 71 |
| FRONTLINE's <i>Being Mortal</i> documentary..... | 72 |
| Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life..... | 73 |
| CONFERENCES | 75 |

FUNDERS

This section profiles select funders active in end-of-life grantmaking. Many have long track records of funding in the space, while a handful are newer and still developing their strategies. A comprehensive catalog of end-of-life funders was beyond the scope of this project, but our list includes many prominent and creative players currently in the space.

Archstone Foundation Long Beach, CA

<http://archstone.org>

History and Overview

Formed in 1985 when FHP, Inc. (a nonprofit HMO) became a for-profit corporation, Archstone Foundation has been a leader in the field of aging and philanthropy for nearly two decades. It helped build the nation's leading affinity group in the field, Grantmakers In Aging, and continues to focus on preparing society to meet the needs of an aging population (especially but not exclusively in California).

Funding Profile

Since its inception in 1985, Archstone Foundation has awarded more than 900 grants with a total value of nearly \$90 million. The Foundation has worked on end-of-life issues since 1988 and invested over \$8 million in support of its End-of-Life Initiative (launched in 2006). Archstone has two levels of grantmaking: Small Grants (which are less than \$15,000 and require approval from a subcommittee of the Board) and Large Grants (which are greater than \$15,000 and require full Board approval).

Funding Priorities

Archstone Foundation undertook major Initiative-based funding from 2005 through 2012 focused on Aging in Community; Depression in Late-Life; Family Caregiving; and Workforce Development. It currently makes grants to sustain, advance, and disseminate work supported during that period. The Foundation also accepts unsolicited Letters of Inquiry on an ongoing basis through its Responsive Grantmaking strategy, but tends not to fund biomedical research, capital campaigns, or fundraising events.

Aging in Community

Archstone invests in innovative support models designed to enable older adults to age independently in their communities. Its "Supportive Communities for Aging Initiative," launched in 2010, funded the development of several "Villages," self-governing grassroots organizations that consolidate and coordinate various services for older adult members. Villages funding concluded in October 2014, but the Foundation hopes to continue supporting these resources through its partnerships. Archstone has also funded efforts like the Program for All Inclusive Care of the Elderly (PACE), shared housing, and low-income housing and services.

Depression in Late-Life

Archstone has partnered with the University of Washington (UW) and the University of California, Davis (UC Davis) to implement the *Care Partners: Bridging Families, Clinics, and Communities to Advance Late-Life Depression Care* project, which will fund innovative approaches to treating depression in older adults through community-engaged partnerships.

Family Caregiving

Historically, Archstone has supported family caregiving through policy and program development, as well as training programs that support family caregivers. More recently, it funded a 2014 Institute of Medicine (now the National Academy of Medicine) study addressing the state of family caregiving and identifying needs for the future; it also explores funding opportunities in this area through its Responsive Grantmaking approach.

Workforce Development

Archstone has funded training and curriculum development in legacy areas (elder abuse and neglect, end-of-life care, and fall prevention), as well as programs focused on housing and behavioral health. The Foundation also supported the Institute of Medicine's (National Academy of Medicine's) 2008 report "Retooling for an Aging America: Building the Health Care Workforce," and was an initial funder of the California State University Institute for Palliative Care.

California HealthCare Foundation Sacramento, CA

<http://www.chcf.org/>
Kate O'Malley, Senior Program Officer
komalley@chcf.org

History and Overview

With offices in Sacramento and Oakland, the California HealthCare Foundation supports efforts to bring Californians better and more affordable care. It funds testing and evaluation of innovative approaches to improving care, and commissions research and analysis to help improve access to coverage and care for low-income Californians, ensure high-value care, and inform decision makers. The Foundation awarded \$30.5 million in 2014.

Funding Profile

As of 2014, the Foundation had assets of \$747.26 million. Total giving for that year was \$42.5 million, with \$30.5 million in grants.

Funding Priorities

The Foundation has a long history granting substantially to promote appropriate care towards the end of life. Primary goals are increasing access to palliative care and aligning care with personal preference in the context of serious illness. The Foundation's work thus far has focused more on providers and health systems, rather than consumers, as levers for change. Recent end-of-life work includes the following:

Appropriate Care Towards the End of Life

This objective has two approaches. The first, increasing access to palliative care, has sought to increase the availability of these services to Californians, first in hospital settings and now in the community. Specifically, the Foundation worked with California's public hospitals to adopt or expand palliative care programs; was an initial funder of the California State University Institute for Palliative Care; and developed the Palliative Care Action Community to support existing efforts to build effective, sustainable, community-based palliative care services in California. Beginning in 2014, CHCF is providing planning and implementation support to nine pairs of payers and providers engaged to deliver palliative care services in the community setting, addressing eligibility criteria, reimbursement and delivery mechanisms, and other metrics for success.

The second area focuses on aligning care with patient wishes. Specifically, the Foundation catalyzed the statewide adoption of Physician Orders for Life Sustaining Treatment (POLST) through promoting awareness and appreciation that patients want to have their end-of-life wishes known and followed; developed new guidelines for nursing homes, aimed at reducing nursing home transfers near the end of life; and initiated work to support civic, faith-based, and healthcare leaders in promoting advance care planning by more Californians.

Health Policy: Policy & Reform

Coalition support: CHCF is an important player in the public engagement area of end-of-life care grantmaking. The Foundation has brought together palliative care providers and coalition leaders to discuss strategies and trends in effectively engaging communities in their work; one of the coalitions CHCF works closely with is the Coalition for Compassionate Care of California.

Innovation: CHCF continually searches for new ways to engage the public. One notable effort in 2013 involved a partnership with a user-centered design studio, Mad*Pow, to create a design challenge calling for innovative avenues to engage patients in advance care planning. The competition garnered entrants from innovators like My Gift of Grace, a card game designed to promote and guide discussion around end-of-life issues. In 2014, the partnership focused on developing tools for shared decision-making between oncologists and patients with advanced lung cancer.

Research: In April 2014, CHCF published a report titled “Advance Care Planning Takes Root: Best Practices from Four California Communities”; the report explored successful community engagement practices by coalitions working across California to improve advance care planning. Statewide surveys in 2006 and 2011 explored Californians attitudes toward death and dying, and “Uneven Terrain,” published in 2015, offers a set of data maps that contrast the estimated need for palliative care with the uneven availability of hospital and community programs in California. Also in 2015, CHCF developed a community-based palliative care resource center on their website, a collection of foundational information to guide program development, reimbursement, and development of metrics to measure success.

Cambia Health Foundation Portland, OR

<http://www.cambiahealthfoundation.org/>
Elyse Salend, MSW, Program Officer
elyse.salend@cambiahealth.com, 503-499-1340

History and Overview

Based in Portland, Oregon, Cambia Health Foundation is the corporate foundation of Cambia Health Solutions, a total health solutions company dedicated to transforming the way people experience health care. Founded in 2007, CHF partners with others to create a more person-focused and economically sustainable healthcare system and to champion the innovators who demonstrate what a truly transformed system can be.

Cambia supports collaborative programs that address the causes of our broken healthcare system and promote the development of new tools and initiatives that overcome barriers to safe, quality care; improve the health of our communities; and encourage deeper engagement along the entire continuum of care. The Foundation works with a wide range of stakeholders and awards grants based on three program areas: Transforming Health Care, Children's Health, and Sojourns (palliative and end-of-life care). The Sojourns program funds in Oregon, Idaho, Utah, Washington, and nationally.

Funding Profile

Since its inception in 2007, the Foundation has granted more than \$40 million, \$25 million of which has supported the Sojourns Program.

Funding Priorities

Cambia has three grantmaking programs: Transforming Health Care, Children's Health, and Sojourns. Sojourns initiatives strive to advance patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. The Foundation is committed to improving access to and quality of palliative care beyond the hospital setting through increased use of technology and expansion in nontraditional settings and rural areas; facilitating an open dialogue about end-of-life issues; strengthening the workforce to meet increased consumer demand; and recognizing leadership, innovation, and inspiration in palliative care.

The Sojourns Scholars Leadership Program makes ten \$180,000 grants per year to emerging leaders in the field of palliative and end-of-life care to support projects and

career development. The goal is to cultivate the next generation of leaders who will shape innovations, policy, and systems to improve the quality of care for individuals living with serious chronic illness and their families. Other initiatives Cambia has supported include the Cambia Palliative Care Center of Excellence at the University of Washington (which the Foundation funded in 2015 with a \$10 million dollar endowment), The Conversation Project Resource Center, various pediatric palliative care programs, and the Center to Advance Palliative Care State-by-State Report Card.

The Fan Fox and Leslie R. Samuels Foundation New York, NY

<http://www.samuels.org/>

Lauren Green Weisenfeld, Deputy Director Healthy Aging Program
212-239-3030

History and Overview

Founded in Utah in 1959 and reorganized in New York in 1981, The Fan Fox and Leslie R. Samuels Foundation has two program areas: Performing Arts and Healthy Aging. The mission of the Foundation's Healthy Aging Program is to improve the healthcare and overall quality of life for New York City's elderly. The Program primarily funds patient-based and social service activities; it aims to improve the way health and social services are delivered by providing support for innovative, effective, efficient, caring, and sustainable programs.

Funding Profile

The Samuels Foundation's annual grantmaking averages \$8 to \$10 million, split evenly between the two program areas. Its palliative care portfolio of current and completed grants totals more than 60 projects, including programs not only in hospitals, but also in nursing homes, hospices, educational institutions, and other settings. Between 2001 and 2013 Samuels invested over \$11.2 million in palliative care grants in NYC; it continues to fund on average \$600,000 to \$1 million annually in this area.

Funding Priorities

The Foundation's Healthy Aging initiatives support aging-in-place, mental health, case management, home care, long-term care, and a host of other programs. As the public's attention turned increasingly toward end-of-life issues, Samuels identified palliative care as an area of interest that could sharply focus its efforts on behalf of older adults. The Foundation has been funding in this area since before 1999; its efforts focus on service delivery and, more recently, on training professionals in the field. It has also partnered with and supported the Center to Advance Palliative Care (CAPC).

Gordon and Betty Moore Foundation Palo Alto, CA

<https://www.moore.org/>
info@moore.org

History and Overview

Established in 2000 by the co-founder of Intel and his wife, the Gordon and Betty Moore Foundation seeks to create positive outcomes for future generations around the world and in the San Francisco Bay Area. The Foundation grants in four program areas: Environmental Conservation, Science, Patient Care, and San Francisco Bay Area.

Funding Profile

Moore manages assets of over \$6.4 billion and has an annual grant budget of roughly \$315 million.

Funding Priorities

The Foundation's Patient Care program is focused on improving the experience and outcomes of patient care. Past work includes initiatives in nursing, ICU care, and patient and family engagement. Moore is currently developing a more focused strategy around end-of-life issues, with an interest in identifying and advancing critical building blocks that create a foundation for improving end-of-life care.

Jewish Healthcare Foundation Pittsburg, PA

<http://www.jhf.org/>

Nancy Zionts, Chief Program Officer, COO
zionts@jhf.org, 412-594-2559

History and Overview

The Jewish Healthcare Foundation (JHF) is a Pennsylvania-based philanthropy that supports a range of health-related efforts across the continuum of care. The Foundation has funded various end-of-life initiatives, including a project called Closure that provides resources to consumers and healthcare professionals dealing with end-of-life issues. JHF also financed the Jewish Association on Aging (JAA), which serves seniors of all faiths, with a commitment of \$33 million.

Funding Profile

JHF's end-of-life grantmaking for 2013 totaled \$1.6 million.

Funding Priorities

Closure

One of JHF's ongoing end-of-life initiatives is the Closure project, which aims to get people thinking and talking about death and advanced care planning. It offers an online self-guided curriculum and a community-led, six-part discussion series, both centered around an evidence-based curriculum. The project serves as "an education, planning, policy, and outreach initiative with a goal of redefining quality care for people with serious illness by raising expectations and empowering them to seek a different health care experience at the end of life – one that aligns with their values, beliefs, and wishes, as well as their health status."

The Last Chapter

JHF also funded an hour-long documentary called "The Last Chapter," which aired on public television in 2011 and highlights the end-of-life experiences of several terminally ill individuals.

Coalition for Quality at the End of Life (CQEL)

JHF has taken a leading role in the Coalition for Quality at the End of Life (CQEL). The Coalition, which is administered by JHF, comprises over 60 leading health systems, providers, insurers, citizen groups, government agencies, philanthropies, and faith-

based organizations who are concerned about the quality of care available to seriously ill and dying individuals and their families in western Pennsylvania.

Pennsylvania POLST

JHF serves as a statewide coordinator for POLST education across the Commonwealth of Pennsylvania. POLST (Physician Orders for Life Sustaining Treatment) are approved medical orders that indicate an individual's treatment preferences. In this capacity, JHF helps to organize in-person "train-the-trainer" sessions across the state and also maintains an online POLST education course. Thus far, over 525 healthcare professionals have participated in 11 POLST train-the-trainer courses held across the state.

RAVEN

JHF serves as the lead education operating partner in a multi-year federal grant project called RAVEN (Reduce Avoidable Hospitalizations Using Evidence-Based Interventions for Nursing Facility Residents). In this capacity, JHF provides targeted education to the frontline staff, leadership, residents, and families of nineteen western Pennsylvania skilled nursing facilities that are participating in the grant. Topics include basics of palliative care, how to engage in conversations about end-of-life with residents/families, how to form a palliative care team within a skilled nursing facility, and quality improvement. Since 2013, JHF has trained over 2,700 through its work in the RAVEN project.

John A. Hartford Foundation New York, NY

<http://www.jhartfound.org/>
Marcus Escobedo, Senior Program Officer
marcus.escobedo@jhartfound.org

History and Overview

The John A. Hartford Foundation is a New York-based foundation established in 1929 that works to improve the health of older Americans. They fund a number of palliative care initiatives and organizations, and have a strong relationship with CAPC (Center to Advance Palliative Care). The Foundation's work on aging issues is financially substantial (almost \$18 million in 2012), and quite broad, encompassing research, activism, hospital centers, and education.

Funding Profile

The Hartford Foundation's 2014 grantmaking totaled \$18.8 million.

Funding Priorities

The Hartford Foundation has funded research, activism, hospital centers, and education around aging and end-of-life issues; notable work includes major support to CAPC (Center to Advance Palliative Care) and the new Hartford Change AGENTS Initiative. Looking forward, the Foundation plans to significantly increase its support in this area, and hopes to spearhead a fresh coalition of funders to develop collective action in the space.

The John and Wauna Harman Foundation Salt Lake City, UT

Julie Berrey, Executive Director
jberrey@jwhfoundation.org

History and Overview

Founded in 1999, the John and Wauna Harman Foundation is a small Utah-based grantmaking foundation with a focus on end-of-life issues, especially in the realm of communication and public engagement.

Funding Profile

The Harman Foundation reported assets of \$8.5 million in 2013.

Funding Priorities

Harman seeks to encourage all Americans to discuss their end-of-life care wishes with loved ones and doctors before serious illness occurs. The Foundation has focused on media and public engagement strategies, including The Conversation Project, the Wake Up to Dying Project, and Prepare for Your Care. Harman has also supported the development of informational films and documentaries, including FRONTLINE's *Being Mortal*, and has partnered with the California HealthCare Foundation to promote community screenings of the film throughout California and to assess its impact. The Foundation is actively exploring additional avenues for funder collaboration.

The Pew Charitable Trusts Philadelphia, PA

<http://www.pewtrusts.org/en>

Josh Rising, Director, Health Care Programs

jrising@pewtrusts.org

History and Overview

The Pew Charitable Trusts, an independent nonprofit, is the sole beneficiary of seven charitable funds established between 1948 and 1979 by the children of Sun Oil Company founder Joseph Newton Pew. Early priorities included cancer research, the Red Cross, and historically black colleges; Pew's work in federal policy began in 1986, and its public opinion research in 1995. In 2002, the Trusts became a public charity and expanded their work internationally.

Funding Profile

In 2015, Pew had assets of around \$5 billion.

Funding Priorities

Pew has a diverse portfolio that includes public opinion research; arts and culture; and environmental, health, state, and consumer policy initiatives. It seeks to improve public policy through rigorous analysis; inform the public with useful data; and invigorate civic life, especially in Philadelphia.

Pew launched its Improving End-of-Life Care project in December 2014. The project seeks to expand access to advance care planning; develop tools to measure the quality of care; highlight innovative ways of providing care to seriously ill people and their families; and improve documentation of patients' wishes for their care near the end of life. Pew's main approach for achieving these goals is federal policy change.

Stupski Foundation San Francisco, CA

<http://www.stupski.org>

History and Overview

The Stupski Foundation is a San Francisco-based foundation begun over 16 years ago as a staff of consultants in more than 30 urban school districts around the country to support bold thinking in K-12 education reform. Having achieved significant progress in this realm, the Foundation spent the past two years redefining its mission and now operates as a grantmaking organization intent on spending down at least \$300 million over the next 10 years. Its new strategies seek to improve the lives of people in California and Hawaii by addressing the issues of hunger, life options for poor and minority youth, and end-of-life care.

Funding Profile

The Foundation intends to spend down at least \$300 million of its assets over the next 10 years.

Funding Priorities

The Stupski Foundation has a history of involvement in K-12 education reform, but recently revamped its strategy to focus on improving the lives of people in California and Hawaii by addressing the issues of hunger, life options for poor and minority youth, and end-of-life care. The Foundation seeks to increase both the effective and informed demand as well as the effective and respectful supply of quality end-of-life care, primarily in its two focus states.

The Foundation is currently evaluating a number of projects submitted for consideration. They do not expect to fund research at this point, with more of an interest on the practical application of knowledge and experimentation with public engagement strategies. The Foundation is very interested in working in concert with other funders.

ORGANIZATIONS

The organizations profiled in this section are mainly nonprofits, but we have also included select businesses and research institutes that do substantial or innovative work around end-of-life issues (especially in the realm of media and public engagement). As with the funders, our list is far from exhaustive but includes many of the field's key players.

ACP Decisions Boston, MA

<http://www.acpdecisions.org>
DBA of the Nous Foundation, Inc.
Dr. Angelo Volandes, President and Co-founder
angelo@acpdecisions.org

History and Overview

ACP (Advance Care Planning) Decisions is a Boston-based nonprofit co-founded in 2009 by Dr. Angelo Volandes, a physician and researcher at Harvard. The organization has a small staff of physicians at some of the top medical centers in the country and seeks to empower patients and families facing medical decisions with a range of video support tools. Its resources are used at 200 different healthcare systems, hospitals, clinics, and nursing homes in the US; while most existing products deal with end-of-life issues, ACP Decisions hopes to expand its services to address other medical decision points.

Core Work

ACP Decisions seeks to empower patients, families, and physicians with accurate and accessible information about care through video resources. Videos are professionally designed and shot, and reviewed by physicians, patients, and patient advocates to ensure accurate and unbiased content.

Relevant Programming

ACP Decisions' earliest videos focused on delivering accurate depictions of end-of-life procedures like CPR and intubation; more recently, they have explored patient decision-making upstream (in contexts like advance care planning). Videos—which are available in several languages—have been well received by patients, and controlled trials have shown that they enhance shared and informed decision-making.

ACP's largest project is in Hawaii, where 15 hospitals, 50 nursing homes, 10 hospices, 200 providers, and 1.4 million residents have access to the entire suite of videos. In the first hospital that adopted the videos, late-stage patients had a 40 percent increase in POLST completions and a 25 percent increase in hospice referrals during the first 18 months of the project.

Center For Practical Bioethics Kansas City, MO

<https://www.practicalbioethics.org/>

John G. Carney, MEd, President and CEO

jcarney@practicalbioethics.org

History and Overview

The Center for Practical Bioethics was founded in 1984 as an independent nonprofit. It helps patients and their families, healthcare professionals, policymakers, and business leaders come to terms with ethically complex issues in medicine and research. The center works in four disciplines: education (public and professional), consultation (consumer and clinical), research and publications, and advocacy and public engagement.

The Center currently operates five programs: Pain Action Alliance to Implement a National Strategy (PAINS), Workplace Programs (CARE), Transportable Physician Orders for Patient Preferences (TROPP), Compassion Sabbath, and Life Sciences. It also puts resources towards hosting events and educational opportunities. In 2014, the Center celebrated the 30th Anniversary Annual Dinner & Symposium, which addressed the theme of patients as teachers.

Core Work

Guided by its conviction that “ethical discourse and action advance the health and dignity of all persons,” the Center seeks to raise and respond to ethical issues in health and healthcare. It operates in the following areas:

- Improving Advance Care Planning & Shared Decision Making
- Changing Chronic Pain Treatment
- Achieving Patient-Centered Outcomes
- Expanding Bioethics Education and Consultation
- Advancing Diversity, Fairness and Justice in Healthcare

The Center’s approaches include:

- using the tools of ethics, based on the principles of philosophy and ethics developed over centuries;
- seizing opportunities to advance awareness of issues and causes;
- bringing diverse, multi-disciplinary groups together to work collaboratively; and
- finding common ground through public and professional education, consumer and clinical consultation, research, publications, public engagement and advocacy.

Relevant Programming

PAINS (Pain Action Alliance to Implement a National Strategy) Project

Inspired by a 2011 Institute of Medicine (now National Academy of Medicine) study that called for “a social transformation in the way that pain is perceived, judged, and treated,” this initiative brings together leaders working in professional societies, patient advocacy organizations, policy groups, people with pain, payers, and the private sector striving together toward a common vision and mission. PAINS operates in three areas: advocacy, engagement, and research. The project has its own website at www.painsproject.org.

Compassion Sabbath

Begun in 1999 with funding from the Robert Wood Johnson Foundation, the Dunn Family Foundation, the Jewish Community Foundation of Greater Kansas City, and Children’s Mercy Hospitals and Clinics, the Compassion Sabbath is an interfaith initiative meant to inspire faith leaders and educators to meet the needs of the seriously ill and their families. The program began in Missouri but now operates across two dozen states. It offers downloadable tools and resources that respects each person’s spiritual needs and advocate for the best clinical care possible, including a toolkit of resources for preaching and worship in many faith traditions; adult education curricula for studying end of life issues and advance care planning; a Caring Conversations workbook that includes advance directive forms; a set of four articles for use on institutional websites, in newsletters, or as bulletin inserts for services of worship; executive summaries reporting on several scientific surveys of faith community members and leaders; and sample brochures of Compassion Sabbath training events.

Workplace Programs (CARE)

The Center’s workplace programming “is designed for corporations as a creative benefit to employees as the Baby Boomers age and find themselves caring for elderly parents and sometimes two other generations of family.” The Center provides informational sessions for a company’s employees with the goals of introducing advance care planning, educating employees about the care patients typically receive at the end of life, and explaining the importance of “the conversation.” The Center also provides a hotline for company employees who need advice related to healthcare decision-making.

Transportable Physician Orders for Patient Preferences (TPOPP)

Designed to improve the quality of end-of-life care, this project translates patient/resident goals and preferences into medical orders (whether the person is in a hospital setting, at a nursing facility, or living independently). TPOPP is modeled on the Physician Orders for Life Sustaining Treatment (POLST) paradigm, one of more than 30 such efforts currently underway nationally to address these issues. TPOPP documents a person’s treatment preferences regarding CPR and the use of mechanical intervention for breathing/ventilation along with other life-sustaining treatments such as tube feedings; translates those preferences into an actionable, portable set of physician orders; communicates them across health settings; and reduces repetitive documentation while complying with state laws and the Federal Patient Self-

Determination Act. The website also provides a TPOPP Toolkit to be used as educational assistance to communities on TPOPP.

Bioethics Channel

The Center for Practical Bioethics maintains a library of audio resources that visitors can download from the website. The podcasts address a variety of issues, including aging and end-of-life care. They are hosted by Center staff but sometimes feature guest contributors.

Events

The Center regularly hosts lectures and events. Recent programming included a 30th Anniversary Dinner & Symposium focused on “Patients as Teachers”; a talk about advanced care planning, shared decision-making, and goals across care; and the 21st Annual Rosemary Flanigan Lecture at the St. Joseph Medical Center in Kansas City, Missouri, where Dr. David Casarett explored the history, science and moral hazards of reviving the “recently dead.”

Funding and Support

The Center for Practical Bioethics “is supported by individual and organizational members, income from consultation work and contracts in communities across the country, and by grants from a number of local and national foundations.” In 2014, the Center received contributions amounting to \$1.6 million and reported expenses of \$1.7 million.

Center to Advance Palliative Care New York, NY

<http://www.capc.org/>

Diane E. Meier, MD, Executive Director

diane.meier@mssm.edu

History and Overview

The Center to Advance Palliative Care (CAPC) is a national nonprofit based at the Icahn School of Medicine at Mount Sinai in New York City. CAPC is a membership organization that prides itself on being a leading resource for palliative care development and growth. CAPC operates with an annual budget of around \$5 million.

Core Work

The mission at CAPC is “to increase the availability of quality palliative care services in hospitals and other health care settings for people facing serious illness, and for their family caregivers.”

Relevant Programming

CAPC is a hub for palliative care best practices, metrics, practical tools, and hands-on technical assistance. CAPC initiatives are designed around creating, providing, and supporting the tools, training, and technical resources necessary to start and sustain successful palliative care programs across the country. CAPC provides clinical and operational CME/CEU online training through multiple platforms; organizes annual seminars for hospital and community-based palliative care clinicians and leaders; provides hands-on mentoring through CAPC’s Palliative Care Leadership Center; and conducts virtual Office Hours allowing “just in time” small-group access to leading experts. CAPC also hosts the National Palliative Care Registry, the nation’s only repository of data on palliative care team characteristics, and promotes public awareness of palliative care issues through the website getpalliativecare.org.

Funding and Support

CAPC's funders include Atlantic Philanthropies, the Altman Foundation, the Brookdale Foundation, the Cambia Health Foundation, the California HealthCare Foundation, the Cameron and Hayden Lord Foundation, The Donaghue Foundation, The Fan Fox and Leslie R. Samuels Foundation, The John A. Hartford Foundation, Livestrong, the Mill Park Foundation, The Olive Branch Fund, the Patty and Jay Baker Foundation, the Robert Wood Johnson Foundation, the Stavros Niarchos Foundation, and The Y.C. Ho/Helen and Michael Chiang Foundation.

Coalition for Compassionate Care of California Sacramento, CA

<http://coalitionccc.org/>

Judy (Citko) Thomas, J.D., Executive Director

jthomas@coalitionccc.org

History and Overview

The Coalition for Compassionate Care of California (CCCC) is a statewide collaborative of organizations and stakeholders dedicated to bringing Californians improved end-of-life care outcomes. Established through the Robert Wood Johnson Foundation's Community-State Partnership Initiative in 1998, CCCC involves legislators, healthcare providers, and the public to tackle deficiencies in end-of-life care.

Among CCCC's successful multi-player initiatives was a massive five-year push to implement the POLST (Physician Orders for Life-Sustaining Treatment) paradigm at treatment centers across California. This involved legislation establishing POLST in state statute, 25 community-based coalitions working on POLST at a local level, a two-day training curriculum on the POLST conversation, a statewide taskforce of stakeholders, a website, and educational materials in several languages. A hallmark of CCCC's POLST work in California was the recognition that successful establishment of POLST required two strategies—one for impacting care on a statewide basis and one for impacting care in communities and at the bedside.

Relevant Programming

1. Advance Care Planning (ACP)

CCCC envisions a healthcare system that reliably provides culturally congruent, quality care that is personalized to end-of-life patients' individual needs and reflective of their wishes. The Coalition is laying the foundations for a ten-year initiative that will engage communities where people live and work, healthcare professionals and organizations, and policymakers and payers.

Public Engagement

CCCC is taking end-of-life discussions out of hospitals and clinics and into the community by coordinating a grassroots initiative to "expand the conversation" about advance care planning.

POLST (Physician Orders for Life-Sustaining Treatment)

CCCC continues to coordinate the implementation of POLST in California, offering trainings and resources to enhance healthcare providers' conversations with patients and families about goals of care.

Advance Care Planning and Healthcare Systems

CCCC partners with various healthcare systems to identify advance care planning needs and to design programs to meet them, including tools, resources and trainings that can be used to educate communities, staff, patients, and families.

People with Developmental Disabilities

CCCC partners with organizations like The Arc and Disability Rights California to help make the conservatorship process more effective and equitable for people with developmental disabilities related to healthcare decision-making.

2. Palliative Care

Through advocacy, education, and resource development, CCCC works to ensure that organizations and communities have the information, knowledge, and tools to sustain and expand palliative care. The Coalition hosts conference calls, webinars, and in-person learning opportunities to spur expansion of palliative care across the continuum of care in California. CCCC's interdisciplinary consultation services include support for healthcare programs seeking to expand their palliative care programs.

Nursing Homes

CCCC encourages nursing homes to recognize the importance of person-centered palliative care and assists them in developing or expanding in-house palliative care programs.

California Palliative Care Summit

Each year, CCCC hosts leaders from around the country at a palliative care summit.

Public Policy

CCCC tracks legislation and educates policymakers to spur changes that increase access to palliative medicine and quality, compassionate end-of-life care.

CCCC is engaged with the California Department of Health Care Services in the implementation of SB 1004; the Coalition also serves as a resource for policymakers and provides coalition members with the latest information on state legislation and policies related to palliative medicine and end-of-life care.

3. Synergistic Impact – Advance Care Planning and Palliative Care

These projects encompass both advance care planning and expanding access to palliative care.

Cultural Diversity and End-of-Life Care

CCCC works to increase cultural sensitivity among healthcare providers who facilitate conversations with or provide care for seriously ill patients and their loved ones by hosting seminars and disseminating research findings.

Faith Community Outreach

To assist community coalitions in connecting with faith communities, CCCC developed a toolkit that includes in-depth information on outreach to local faith leaders and hosting introductory seminars on advance care planning and end-of-life and palliative care.

Funding and Support

CCCC's income and expenses in 2012 were \$1,029,442 and \$1,000,905, respectively. The Coalition's funders have included the Robert Wood Johnson Foundation, the California HealthCare Foundation, and the California Department of Developmental Services.

Coalition to Transform Advanced Care Washington, DC

<http://advancedcarecoalition.org/>
CTAC@advancedcarecoalition.org

History and Overview

The Coalition to Transform Advance Care (C-TAC) is a DC-based alliance of individuals and entities working to “provide all Americans, especially the sickest and most vulnerable, with comprehensive, high quality, person- and family- centered care that is consistent with their goals and values and honors their dignity.” C-TAC is co-chaired by Tom Koutsoumpas of the Caring Foundation and Bill Novelli of the McDonough School of Business at Georgetown University.

Relevant Programming

C-TAC seeks to create lasting change in the social, political and health care environment, by (1) knowing how patients and providers understand and make decisions about advanced care, (2) acting to implement health system, social, and political reform, and (3) sustaining the reform. Programming includes:

1. Community Action Project

C-TAC has initiated the Community Action Project to bring together health systems and community-based organizations to improve advanced illness care. The Project has four key elements: 1) a community-specific needs assessment; 2) a convening of patients and caregivers, community organizations, and health systems; 3) necessary technical assistance (e.g., strategic plan, communications, education on advanced illness); and 4) a resource-sharing tool to facilitate the dissemination of best practices from member organizations.

2. Advanced Care Project

This project is a national collaboration among health plans, health systems, a range of clinicians and related organizations, community-based groups, and other stakeholders to identify, analyze, and implement best practice clinical care models to improve care for patients and families living with advanced illness.

3. Policy & Advocacy

Moving forward in 2015, the Policy Agenda will help direct the Coalition’s advocacy efforts as a coalition and will be continuously revised and renewed as findings from priority projects such as the Advanced Care Project (ACP) and the Community Action Project (CAP) are released.

Funding and Support

The C-TAC's funders include the Peter G. Peterson Foundation and The SCAN Foundation.

The Conversation Project

<http://theconversationproject.org>

Ellen Goodman, Co-Founder and Director

ellen.goodman@me.com

History and Overview

Co-founded in 2011 by Pulitzer Prize winner Ellen Goodman and a group of media, clergy, and medical professionals, The Conversation Project provides resources and support to help people talk about their wishes for end-of-life care. The Institute for Healthcare Improvement (IHI), a primary partner, describes the Conversation Project as a “public engagement campaign advocating ‘kitchen table’ conversations with family and friends about wishes for end-of-life care.”

Core Work

TCP encourages everyone to talk—first with their loved ones and then with their clinicians—about the type of care they would like at the end of their lives. Conversations should take place early and often around the kitchen table, before there is a crisis at the bedside.

Through three intertwined programming strategies—a national media campaign, tools that encourage every person to express his or her wishes, and an array of grassroots community initiatives—TCP seeks to fuel broad change in our culture. TCP believes society is on the brink of recognizing the importance of addressing end-of-life care issues openly and honestly with loved ones and care providers, and hopes to help ignite this critical change.

Relevant Programming

The Conversation Project has developed a three-pronged strategy to promote culture change.

1. Raise public awareness of the need for timely conversations about how we want to live at the end of our lives. TCP has launched a successful national media campaign through its website and outreach to both traditional and social media. The organization has been featured in *The New York Times*, *The Wall Street Journal*, *O Magazine*, *Women’s Day*, the *Harvard Business Review*, *NPR’s Here and Now* and *All Things Considered* and other publications and broadcasts, including segments on *ABC World News with Diane Sawyer* and *NBC News with Nancy Snyderman*. TCP has also established an active presence on Facebook and Twitter and is linked to other social media platforms.

2. Provide the tools to help everyone have The Conversation. TCP's website features ideas and techniques to help visitors have *the conversation* with their loved ones and clinicians, and encourages visitors to share their stories and perspectives. The website offers a free, user-friendly **Conversation Starter Kit** providing encouragement and step-by-step guidance on having *the conversation*, as well as a parallel kit focused on talking to care providers. Both kits are also available in Spanish, French, Mandarin and Hebrew. At the request of clinicians and parents, TCP has just published a Starter Kit for Parents of Critically Ill Children, and they are currently designing a Starter-Kit for Families with a Loved One with Dementia. More than two-thirds of the visitors to TCP's website have chosen to download at least one of these starter kits.

In response to numerous requests from doctors, TCP has also created a free online curriculum to help health professionals have *the conversation* in both their personal and professional lives. The curriculum fosters skills that may have been missing from these professionals' training. TCP is considering a starter kit focused on doctor-patient conversations.

3. Bring The Conversation to people where they live, work, and pray – "Conversation-Ready Communities." To maximize its impact, TCP seeks to spread not only on the air but also at the grassroots. TCP works actively with over 250 communities across the country to help them become "Conversation-Ready," and has created a forum for local leaders to share experiences and create their own learning communities.

TCP is also working with the American business community. Major companies like Dow, Goodyear, Blue Cross Blue Shield of Massachusetts, and Tufts Health Plan have invited TCP into their worksites to address their leadership, to share resources, and/or to coach key staff members to speak to the importance of *the conversation* with their employees or retirees – an increasing number of whom are also caregivers to loved ones and eager for additional resources.

TCP is also collaborating with religious congregations and clergy from each of the major faith traditions. They are piloting this effort in the Boston area to determine how best to inspire and empower clergy and lay leaders to implement *the conversation* within the doctrinal framework of their respective religions. They expect to build upon this pilot and expand their efforts nationally.

Partnerships

The Conversation Project is in community partnership with 250 communities in 42 states. Additionally, the Institute for Healthcare Improvement is a major partner, as is the Cambia Health Foundation's Sojourn Program, which worked with TCP to make tools publicly available through a virtual Community Resource Center.

Funding and Support

TCP receives 75 percent of its funding from foundations (including healthcare, community, and family foundations, as well as major national foundations) and 25 percent from fees and donations. Early supporters include The Schwartz Center, the Cummings Foundation, and the Cambia Health Foundation.

The Hastings Center Garrison, NY

<http://www.thehastingscenter.org/>

Susan Gilbert, Public Affairs and Communications Manager

gilberts@thehastingscenter.org

History and Overview

Founded in 1969 as a nonprofit, nonpartisan bioethics research institute, The Hastings Center was integral in establishing bioethics as a field of study. Its scholarship addresses five principal areas: health and health care; children and families; aging, chronic conditions, and care near the end of life; emerging science and conceptions of the self; and human impact on the natural world. The Center supports leading researchers in bioethics through its fellowships and visiting scholars program. Its projects aim to inform professional practice, public discourse, and social policy. Bioethics, and not specifically palliative care, is the primary lens through which The Hastings Center works.

Core Work

The Hastings Center seeks to build, communicate, teach, and publish bioethics. Its mission is to pursue interdisciplinary research and education that includes both theory and practice; to engage a broad audience of thoughtful people in the work of the Center; to collaborate with policy makers, in the private as well as the public sphere, to identify and analyze the ethical dimensions of their work; and to strengthen the international dimensions of the Center's work.

Relevant Programming

The Hastings Center administers various events, research initiatives, and public advocacy projects. Highlights relevant to end-of-life care include the following:

The Hastings Center Cunniff-Dixon Physician Awards

The Hastings Center offers a financial prize awarded to physicians who have shown exemplary care for their patients, modeled good medicine for other physicians, and advanced the centrality in end-of-life care as a basic part of the doctor-patient relationship. There are five annual prizes totaling \$95,000: one prize of \$25,000 for a senior physician, one prize of \$25,000 for a mid-career physician, and three prizes of \$15,000 for early-career physicians.

The Hastings Center Report

The Center publishes its Report, the oldest bioethics journal, six times per year; it covers various ethical, legal, and social issues in medicine. Recent issues feature several articles related to end-of-life care.

Over 65 Blog

The Hastings Center hosted this blog from 2012–2014; though it was not specifically aimed at palliative or end-of-life care, it was a platform for seniors navigating the healthcare system. The blog is archived on the Center's website.

Bioethics Forum

The Bioethics Forum is the blog of the Hastings Center Report. Though it doesn't focus exclusively on end-of-life care, it regularly features relevant posts.

Funding and Support

The organization draws its funding from research grants, charitable contributions, and reserve fund income. In 2013, the Center reported \$3.3 million in operating support and revenue, of which \$2.3 million came from grants, gifts, and other contributions, while \$367,601 came from government grants.

National Academy of Medicine Washington, DC

<http://www.nam.edu/>

Adrienne Butler, Study Director
astith@nas.edu

History and Overview

Formerly the Institute of Medicine (IOM), the National Academy of Medicine (NAM) is a nonprofit organization that is part of the National Academies. Its research covers a range of medical topics and has included crucial contributions to the field of end-of-life care, notably a seminal study in 1997 and a follow-up report in 2014.

Core Work

NAM's aim is to help those in government and the private sector make informed health decisions by providing evidence upon which they can rely.

Relevant Programming

NAM has produced two key reports on end-of-life issues, both profiled at greater length in the introduction to this scan.

Approaching Death: Improving Care at the End of Life

NAM's most significant contribution to the field came in 1997, with the publication of "Approaching Death: Improving Care at the End of Life." Funded partly by the Robert Wood Johnson Foundation, the report engaged a committee of experts that set out to define what comprised a "decent or good" and "bad" death, and to make a series of recommendations to strengthen (or create) palliative and hospice care and encourage public conversations about dying. The Committee identified deficiencies in clinical education and research gaps, as well as a general discomfort with conversations about death and dying. They compiled a series of "Recommendations and Future Directions" to guide policymakers, organizations, physicians and patients towards more compassionate, informed, and effective end-of-life care.

Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

Following up on its landmark "Approaching Death" report, NAM recently released a new study titled "Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life." The report draws on literature, expert commentary, and public feedback to review key elements of end-of-life care in the US, highlighting important

conclusions and recommendations. The report finds that palliative care remains absent from many medical and nursing school criteria; that end-of-life patients frequently receive fragmented care from multiple specialists instead of team-based palliative care; that certain policy issues surrounding Medicare incentivize the use of superfluous end-of-life services; that there is a need for public engagement and education on end of life issues, as well as a need to de-stigmatize the conversations around death and dying that are so essential to one's wellbeing.

Lown Institute Brookline, MA

<http://lowninstitute.org>

History and Overview

Founded in 2012 by renowned cardiologist and humanitarian Bernard Lown, the Lown Institute works to catalyze a grassroots movement for transforming healthcare systems and improving the health of communities. Lown advocates for a redirection of resources currently being wasted in healthcare towards promoting community health and redressing health disparities. Through grassroots efforts centered around a convening of clinicians and patients called the RightCare Alliance, Lown seeks to strengthen the clinician-patient relationship, reduce preventable harm, eliminate the use of ineffective or unwanted treatments, and ensure that all people have access to affordable and appropriate medical care. The Institute envisions a financially efficient system where healthcare delivery is locally controlled.

Core Work

Lown's programming seeks to grow and support the Right Care Movement, a grassroots alliance of clinicians, patients, policymakers, and community leaders working toward a more just, compassionate, effective, and affordable healthcare system, where medical tests and treatments are not overused and where patients' wishes are respected.

Relevant Programming

Lown holds annual conferences and maintains a library of published research addressing the overuse of medical tests and treatments and its consequences, as well as a collection of personal stories from patients affected by overuse. The Institute's **RightCare Alliance Young Innovator Grants** provide up to \$7,000 of funding to support pilot programs that teach trainees to recognize and avoid overuse, build more meaningful relationships with patients, and provide ethical compassionate care. Lown's **RightCare Rounds** program, designed to be implemented at healthcare institutions, uses case studies and evidence-based discussions to help clinicians recognize and avoid overuse before it occurs. The Institute's **Do No Harm Project** uses clinical vignettes written by trainees to improve recognition of the harms that can result from medical overuse.

Funding and Support

Major current and past funders include the Agency for Healthcare Research and Quality; the California HealthCare Foundation; the Fannie E. Rippel Foundation; Kaiser Permanente; the Markle Foundation; the Mattina R. Proctor Foundation; the New America Foundation; and the Robert Wood Johnson Foundation.

MyDirectives.com
Richardson, TX

<https://mydirectives.com>

Overview and History

Launched in 2012, MyDirectives is the first completely online advance care planning service that is secure, legal, and free to consumers. It is also the first advance care platform to receive “meaningful use” certification from HHS, which allows eligible hospitals to receive incentive payments from Medicare and Medicaid when using the technology. MyDirectives is a supporting organization of the Blue Button program to allow downloadable personal health records.

Core Work

The organization’s Universal Advance Digital Directive (uADD)TM, the first all-digital directive used worldwide, simplifies more than 200 legalistic forms used in Asia, Europe, and the US to help consumers record their medical treatment wishes, preferences regarding palliative and hospice care, organ donation, and autopsy, and other critical personal information. Users can record their wishes using various formats, including video. MyDirectives then makes this data securely and immediately available. MyDirectives is accessible both online and as a mobile app.

Funding and Support

MyDirectives is a service of ADVault, Inc., a privately held US corporation that generates most of its revenue by charging public and private health plans, healthcare providers, and healthcare information technology vendors. The service is free to consumers.

National Hospice and Palliative Care Organization Alexandria, VA

<http://www.nhpco.org>

History and Overview

Founded in 1978 as the National Hospice Organization, the National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the US. The organization advocates for the terminally ill and their families; develops public and professional educational programs and materials to enhance understanding and availability of hospice and palliative care; convenes frequent meetings and symposia on emerging issues; provides technical informational resources to its membership; conducts research; monitors Congressional and regulatory activities; and works closely with other organizations concerned with end-of-life care. NHPCO is affiliated with the National Hospice Foundation; Global Partners in Care; and the Hospice Action Network.

Core Work

Through its various committees, advisory councils, and affiliates, NHPCO supports hospice and palliative care patients and providers with resources, programming, research, and advocacy.

Relevant Programming

In addition to its Governance Committee, NHPCO maintains four Committees and five Advisory Councils that reflect important areas of programming. The Committees include a **Professional Education Committee**, which helps oversee NHPCO's Professional Development program; a **Public Policy Committee**, which monitors congressional and administrative activity on hospice and palliative care issues and helps develop NHPCO's legislative agenda; a **Quality & Standards Committee**, which oversees NHPCO's national quality program and other NHPCO programmatic activities, and updates the *NHPCO Standards of Practice for Hospice Programs*; and a **Regulatory Committee**, which closely monitors federal activity around hospice and palliative care issues. The Advisory Councils include a **Diversity Advisory Council**; a **Global Partners in Care Advisory Council** (which provides strategic guidance for international partnership development and financial support for Global Partners in Care); an **Ethics Advisory Council**; a **Palliative Care Advisory Council**; and a **Pediatrics Advisory Council** (comprised of members from NHPCO's Children's Project on Palliative/Hospice Services, or ChiPPS).

Other NHPCO initiatives include:

The Mary J. Labyak Institute, founded in 2012 at the National Center for Care at the End of Life to develop and promote progress and strategies ensuring the best possible care for patients and families. The Institute is organized into five centers: the Center for Children; the Center for Grief and Bereavement; the Center for Leadership Development; the Center for Spiritual Care; and the Center for Veterans' Care. Its activities include convening experts to create new care models; publishing articles, briefings, and other communications aimed at promoting innovation; identifying, packaging, and disseminating promising practices and innovative programs; and infusing hospice values into the work of NHPCO and stakeholders.

NHPCO Edge offers consulting services to hospice and palliative care providers; recent engagements include strategic planning, market analysis, board retreat, and bed need assessment projects.

Quality Partners, NHPCO's national performance improvement program, offers hospice providers a framework for a 360-degree surveillance of both clinical and non-clinical areas to facilitate assessment and quality of care monitoring and determine areas in need of improvement. The program offers resources and tools on various measures of quality and performance, quality reporting, and staffing guidelines.

The Hospice Action Network (HAN) is NHPCO's lobbying affiliate and national hospice advocacy organization. Dedicated to preserving and expanding access to hospice care in America, HAN connects Hospice Advocates with each other, the media, the general public, and policymakers; it also provides tools and resources to Hospice Advocates.

The Children's Project on Palliative/Hospice Services (ChiPPS), NHPCO's pediatric advisory council, publishes a quarterly e-journal and offers online courses, training, conferences, educational brochures, and other resources to families and providers.

NHPCO's **Online Learning** resources include webinars held twice a month; on-demand webcasts and online courses; and Hospice Manager Development Program Online Learning Modules, the only hospice-specific comprehensive management training program. NHPCO also offers a Hospice Executive Leadership Program.

NHPCO's publications include ***NewsBriefs***, a weekly e-newsletter; ***NewsLine***, a digital magazine for members; the ***Hospice and Palliative Care Buyer's Guide***; the ***Journal of Pain and Symptom Management***, a peer-reviewed journal published monthly and whose readership extends to the broader medical community; two targeted e-newsletters, the ***Regulatory Round-Up*** and the ***ChiPPS Pediatric Palliative Care Journal***; and position statements on various topics in palliative and end-of-life care, as well as a general list of Ethical Principles, *Hospice Standards of Practice*.

NHPCO convenes an annual **Clinical Team Conference and Pediatric Intensive** and an annual **Management and Leadership Conference**.

Funding and Support

In 2014, NHPCO generated 58 percent of its revenues from dues, 19 percent from conferences, and 16 percent from contracts, grants, and contributions.

PREPARE for Your Care

<http://www.prepareforyourcare.org>

Rebecca Sudore, MD, author

rebecca.sudore@va.gov

History and Overview

Launched in 2013 by researchers at the San Francisco VA Medical Center (SFVAMC), UCSF, and the Veterans Health Research Institute (NCIRE), PREPARE is an online resource that helps users make and communicate complex medical decisions involving end-of-life care. Rebecca Sudore, MD, helped develop the site after publishing a study in the *Journal of Pain and Symptom Management* that identified gaps in planning for decisions about serious illness among a culturally diverse group of patients and surrogate decision-makers. Sudore, who also worked with the Institute for Healthcare Advancement to create an easy-to-read, free, and multilingual advance directive for California, sought to supplement advance directives with a value-driven and easy-to-use tool to prepare people for making and communicating medical decisions.

Core Work

PREPARE offers an easy-to-use, step-by-step guide to help people make and effectively communicate decisions about their medical care. The site's audio-visual interface targets underserved populations, including patients with low computer literacy, low health literacy, and/or visual or hearing impairments. All text is written at a fifth-grade reading level and presented in large font with voiceovers and closed-captioning available, and the site also includes videos. Content is available in Spanish and English.

Funding and Support

Funders include The S.D. Bechtel, Jr. Family Foundation; The National Palliative Care Research Center; The Hellman Family Foundation; and the National Institute on Aging.

The Wake Up to Dying Project

<http://www.wakeuptodyingproject.org>

Nina Thompson, Executive Director

nina@wakeuptodyingproject.org

History and Overview

Founded in 2013, the Wake Up to Dying Project is an awareness and action campaign that encourages people to think and talk about dying. The project uses storytelling, art, and other hands-on activities to promote awareness and conversation around end-of-life issues. The organization's team includes radio producers, nurses, social workers, and consultants.

Core Work

The Wake Up to Dying Project envisions itself as an awareness and action campaign using the power of story to explore death, dying, and life.

Relevant Programming

The Wake Up to Dying Project gathers stories about death and dying and shares them via its website; social media platforms; and a traveling exhibit. The exhibit features first-person audio stories, information about local end-of-life resources, and workshops with local leaders in end-of-life care. The organization has plans to offer podcasts, PSAs, print campaigns, workshops, presentations, and opportunities for engagement through discussions and volunteer work.

HISTORICAL FUNDERS

This section profiles funders no longer substantially involved in end-of-life grantmaking, but whose contributions to the space were significant enough to be of interest to present-day funders.

Robert Wood Johnson Foundation Princeton, NJ

<http://www.rwjf.org/>

Rosemary Gibson, Senior Program Officer
rosemarygibson100@gmail.com

History and Overview

The Robert Wood Johnson Foundation is a New Jersey-based foundation that has been dedicated solely to public health grantmaking for the past 40 years. Its end-of-life care grantmaking dates back to the 1980s, when it convened researchers to discuss opportunities in the field and subsequently decided to commission the largest study ever done on the issue, SUPPORT—Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. SUPPORT research took place between 1986 and 1994, and surprised the field by concluding that Americans were not getting the end-of-life care they desired or deserved. What the foundation had assumed to be the best strategy for intervention in the field—enhancing patient-physician communication and enhancing the access to information on treatment success rates—proved completely ineffective. SUPPORT is often credited with establishing a foundation for the entire field of end-of-life care.

Funding Profile

RWJF funded end-of-life work from the late 1980s through 2006. End-of-life grantmaking totaled \$170 million, plus over \$20 million toward SUPPORT.

Funding Priorities

RWJF made its first three grants post-SUPPORT to Last Acts®, Promoting Excellence in End-of-Life Care, and Education in Palliative and End-of-Life Care. RWJF's strategy focused on:

“Professional education: changing the curriculum in medical and nursing schools, modifying courses and textbooks to include end-of-life care, adding palliative care to licensure and certification examinations, training medical and nursing school faculty and practitioners, and supporting articles for professional journals such as the Journal of the American Medical Association and the American Journal of Nursing.

Institutional change: building palliative care capacity in the nation's hospitals, where more than half of Americans die; working with hospital accreditation

agencies to develop pain management standards; and stimulating innovative programs that provide palliative care.

Public engagement: creating a new vision of end-of-life care through the media (both information and entertainment), and getting individuals and communities to take action to improve care for dying people and their families.”

Public Engagement

Two important grantees in the realm of public engagement were Last Acts, a national communications campaign that ran until 2005 and brought together over 800 national health and consumer groups; and the four-part series "On Our Own Terms: Moyers on Dying", which aired in September, 2000 on PBS and aimed to explore the various aspects of dying.

Reports

RWJF commissioned a study in 2011 titled “Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field,” a key overview of grantmaking in the space. The authors offer a comprehensive picture of RWJF’s focus areas and how their strategy evolved over time. Additionally, RWJF has commissioned and written a number of reports on its overall work, many of its specific programs, and areas of interest within end-of-life and palliative care.

Open Society Institute/Open Society Foundation New York, NY

http://www.opensocietyfoundations.org/sites/default/files/a_transforming.pdf

Kathleen Foley, M.D., Former Director, Project on Death in America
646-888-2683

History and Overview

Unlike most profiles in this scan, the following pages outline a foundational program within an organization. Open Society Institute's long-term program, "The Project on Death in America" (PDIA), warrants a detailed breakdown given its seminal contribution to the field of palliative care.

Founded in 1993 by investor and philanthropist George Soros, the Open Society Foundation (OSF)—formerly the Open Society Institute—is a private foundation based in New York City. In 1994, OSF initiated the Project on Death in America (PDIA), which would spend nine years distributing \$45 million to address seven priority areas in end-of-life care. More than half these funds went to professional development initiatives for medical professionals and social workers. The project recognized that faculty members and clinicians would spearhead meaningful changes around end-of-life care, and help achieve the project's goal of transforming the experience of dying in the US. The Project on Death in America's advisory board was led by Kathleen Foley, M.D., a neurologist and chief of the pain and palliative care service at Memorial Sloan-Kettering Cancer Center in New York City.

In 2002, George Soros announced the reorganization of his foundations network, effectively ending PDIA. Though the project had made significant inroads in the field of palliative care, much work remained to be done. Upon completing PDIA's grantmaking at the end of 2003, OSF commissioned a report to inform others about the strategies and lessons learned from the nine-year Project on Death in America. The report, summarized later in this scan, outlines the three eras in PDIA's grantmaking and offers recommendations for future funders so that the legacy of PDIA's work may continue.

Funding Profile

By the end of nine years, PDIA had granted \$45 million, more than half of which went to professional development programs for medical professionals and social workers.

Funding Priorities

First Phase: 1994-1997

Over nearly a decade, OSF initiated three stages of PDIA funding. In the first era (1994 through 1997), OSF identified seven priority areas for funding, with a focus on changing the culture of medicine from inside the hospitals and nursing homes where approximately 70 percent of Americans die. Accordingly, professional development was fundamental to the project's grantmaking efforts, during this period and through the final grants in 2003. PDIA initiated professional scholarship and leadership programs such as the Faculty Scholars Program and the Social Work Leadership Development Awards, which became long-standing elements of its work. Between 1994 and 1997, the Project on Death in America received more than 2,000 grant requests over four grant cycles and funded 122 projects. Grants ranged from \$5,000 to \$400,000 and supported numerous disciplines contributing to end-of-life issues, from the medical to the philosophical to the political.

Second Phase: 1997-2000

During the second phase in the late-1990s, the project expanded its grantmaking to support community arts and education, as well as address the challenges that underserved communities face. The arts and humanities became important media through which individuals and communities could express experiences of illness, death, and grief to facilitate conversation and reflection. PDIA also funded interfaith, community-based, and school-based programs that supported individuals and groups in the bereavement process. Finally, PDIA challenged legal and economic barriers that hindered quality end-of-life treatment for vulnerable populations and groups likely to be marginalized by the palliative care system (including children, the elderly, non-English speakers, the incarcerated, the homeless, members of racial or cultural minorities, and people with physical or developmental disabilities).

Final Phase: 2000-2003

PDIA's final stage of grantmaking focused on institutionalizing change by "building a sustainable field of palliative care, with the sufficient infrastructure and leadership to dismantle the barriers that still kept people from receiving excellent care." They forged partnerships with other funders, including the Emily Davie and Joseph S. Kornfeld Foundation. Among the project's final grants were a \$1.2 million grant awarded to the American Academy of Hospice and Palliative Medicine.

Partnerships

From the outset of the project, PDIA fostered cooperation and collaboration among professionals across various medical, political, and philanthropic fields. In 1995, PDIA, along with the Nathan Cummings Foundation, the Robert Wood Johnson Foundation, the Rockefeller Family Office, and the Commonwealth Fund, formed Grantmakers Concerned with Care at the End of Life. The coalition was meant to expand funding partnerships and to be a resource for other foundations hoping to support end-of-life care. However, it does not appear to have outlasted PDIA.

In its last stage of funding between 2001 and 2003, PDIA joined forces with the Emily Davie and Joseph S. Kornfeld Foundation to collaboratively grant almost \$2 million to several palliative care fellowship programs across the country. Palliative care continues to be an important issue for the Foundation.

Findings and Recommendations

Reflecting on OSF's end-of-life grantmaking, the advisory board found that the greatest barriers to quality end-of-life care included inadequate training, weak institutional commitment to end-of-life care, the absence of appropriate funding structures, a lack of quality measures, and major gaps in the research base. PDIA outlined five areas of impact in the field of end-of-life and palliative care:

- Public Engagement
- Professional Education
- Research
- Clinical Care
- Public Policy

These represent opportunities for maximum leverage, “where even modest philanthropic investment will yield significant impact.”

AFFINITY GROUPS

Grantmakers in Aging (GIA) Arlington, VA

<http://www.giaging.org>

John Feather, PhD, Chief Executive Officer

jfeather@giaging.org, 703.413.0413

Founded in 1982 (and incorporated as a 501(c)(3) in 1998), Grantmakers in Aging is a Virginia-based membership organization that works to support philanthropic activity dedicated to improving the experience of the aging population. As of December 2014, GIA's roster listed nearly 100 members. The Hartford Foundation, a longstanding member, continues to provide core funding for GIA.

GIA organizes annual conferences; partners with the Pfizer Foundation to support **Community AGenda**, an initiative that helps promote and develop age-friendly communities; partners with regional associations of grantmakers to encourage aging-related funding through its **EngAGement** initiative; holds regular webinars on topics of interest; maintains an extensive catalog of resources on aging-related issues ranging from arts and culture to financial exploitation to disasters to technology, and including hospice care; and publishes an e-newsletter, **Aging Matters**, as well as briefs and reports. GIA's 2013 conference included a session on honoring older people's end-of-life wishes, and the 2014 conference held a session based on the Institute of Medicine's (now National Academy of Medicine's) reports on aging and health. The 2015 conference will take place in October.

Grantmakers in Health (GIH)

Washington, DC

<http://www.gih.org/>

Osula Rushing, M.S., Vice President for Program and Strategy

orushing@gih.org

Formally launched in 1982, Grantmakers in Health (GIH) is a DC-based nonprofit that supports foundations and other grantmakers in funding health-related areas. Its mission is to foster communication and collaboration among grantmakers and others, and to help strengthen the grantmaking community's knowledge, skills, and effectiveness. With more than 200 funding partners, GIH hosts conferences and webinars and provides bulletins, briefs, and other resources on the field.

GIH's website tracks developments within various issue areas, including "Health Across the Life Course;" this field has a subcategory for news and resources around aging.

Colin Pekruhn (cpekruhn@gih.org) is responsible for GIH's aging-related programming.

KEY LITERATURE

This section briefly summarizes literature—studies, reports, books, and films—that has deeply informed the field of end-of-life care.

SUPPORT Principal Investigators.

A controlled trial to improve care for seriously hospitalized patients. JAMA 1995; 274(20):1591-8

<http://jama.jamanetwork.com/article.aspx?articleid=391724>

Two decades after its 1995 publication, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) remains a seminal element of the literature around end-of-life care in the US. Funded by the Robert Wood Johnson Foundation, the study sought to “improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying.” It involved two phases, and a total of 9105 adults hospitalized with one or more of nine life-threatening diagnoses. Phase I consisted of a two-year prospective observational study, and Phase II was a two-year controlled clinical trial involving 4804 patients and their doctors, who were randomly grouped into an intervention group (n=2652) and a control group (n=2152) across five teaching hospitals throughout the US.

The Phase I observation revealed that clinicians did not often follow patient preferences, highlighting “shortcomings in communication, frequency of aggressive treatment, and the characteristics of hospital death: only 47% of physicians knew when their patients preferred to avoid CPR; 46% of do-not-resuscitate (DNR) orders were written within 2 days of death; 38% of patients who died spent at least 10 days in an intensive care unit (ICU); and for 50% of conscious patients who died in the hospital, family members reported moderate to severe pain at least half the time.”

In Phase II, the intervention group (physicians and patients) received various forms of supplemental information and support. Physicians were given “estimates of the likelihood of 6-month survival for every day up to 6 months, outcomes of cardiopulmonary resuscitation (CPR), and functional disability at 2 months”. Specially trained nurses communicated with patients, families, physicians, and hospital staff to gather preferences, increase understanding of outcomes, attend to pain control, and enable advance care planning and facilitate communication between patients and physicians.

The results were discouraging: there was no improvement in any of the five targeted outcomes in the intervention group. These five areas were “physician understanding of patient preferences; incidence and time of documentation of do-not-resuscitate (DNR) orders; pain; time spent in an intensive care unit (ICU), comatose, or receiving mechanical ventilation before death; and hospital resource use.” Patients “experienced no improvement in patient-physician communication (e.g., 37% of control patients and 40% of intervention patients discussed CPR preferences) or in the five targeted outcomes, i.e., incidence or timing of written DNR orders (adjusted ratio, 1.02; 95%

confidence interval [CI], 0.90 to 1.15), physicians' knowledge of their patients' preferences not to be resuscitated (adjusted ratio, 1.22; 95% CI, 0.99 to 1.49), number of days spent in an ICU, receiving mechanical ventilation, or comatose before death (adjusted ratio, 0.97; 95% CI, 0.87 to 1.07), or level of reported pain (adjusted ratio, 1.15; 95% CI, 1.00 to 1.33). The intervention also did not reduce use of hospital resources (adjusted ratio, 1.05; 95% CI, 0.99 to 1.12)."

Phase I of the SUPPORT study had found substantial shortcomings in end-of-life care in the US. Since enhancing patient-physician communication and "realistically forecasting outcomes of life-sustaining treatment" was at that time thought to be the most promising method for improving patient outcomes and care, Phase II studied an intervention group that received enhanced opportunities for greater communication between physicians and patients. The results, however, showed this method to be ineffective: efforts to enhance communication and information regarding life-sustaining treatments did not improve patient care or outcomes.

The authors presented a likely reason for the lack of improvement: "Because there was no movement toward what would seem to be better practices, one could conclude that physicians, patients, and families are fairly comfortable with the current situation." While physicians were willing to participate, it appears that their behavior remained unchanged, possibly because while they recognized the larger problem, their immediate actions seemed to be the best they could do within the existing system of care. Hence, the SUPPORT study concluded that merely seeking to improve communication and information will not "improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying." Instead, the authors argued that much more proactive, forceful, and creative efforts to shape end of life treatment in the US are needed. However, the authors offered no specific examples or recommendations of what such future efforts would entail.

"Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field"

<http://www.rwjf.org/content/dam/farm/reports/reports/2011/rwjf69582>

The Robert Wood Johnson Foundation commissioned "Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field", published in 2011, soon after its grantmaking in end-of-life care ended in 2006. The report sought to "understand the impact of this body of work and to monitor the state of the field into the future." Between 1996 and 2006, RWJF had invested over \$170 million to improve care at the end of life, consisting of over 300 grants and support for hundreds of coalitions across the country. To analyze and reflect on this work, the report's authors divided the document into seven sections, which approach the context of the work, the emergence of RWJF's strategy, the bulk of programmatic initiatives, and a look at the state of the field in 2011.

Background: SUPPORT

The Robert Wood Johnson Foundation's engagement in end-of-life care began with its first major initiative, funding SUPPORT (*Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments*, detailed above). RWJF first funded SUPPORT in 1986 and through 1994, and "quickly learned that its effects set the stage for the future of what was to become the field." Phase I of SUPPORT found substantial shortcomings in end of life care in the US; Phase II studied an intervention group that received enhanced opportunities for greater communication between physicians and patients. Unexpectedly, the intervention group failed to show improved outcomes: patient preferences for end-of-life care continued to be disregarded or rarely communicated. The report made national news, and created the momentum that many consider to have catalyzed grantmaking for end-of-life care initiatives.

Following the unexpected results of SUPPORT, RWJF entered two years of reflection. Foundation staff met with experts from across the field to construct a new grantmaking strategy. It was out of this effort that RWJF made its first three grants: Last Acts, Promoting Excellence in End-of-Life Care, and Education in Palliative and End-of-Life Care. The Foundation's work focused heavily on enhancing the state of palliative care knowledge and practice in the US.

Early Initiatives

RWJF's first three end-of-life grants, informed by the two years following the SUPPORT release, were:

Last Acts

"Last Acts was able to capitalize on the growing interest in end-of-life care issues and became an important source of information, as well as an organizing entity for local advocates." Last Acts supported a large community of organizations working on end-of-life care initiatives at the local, regional, and national levels.

Promoting Excellence in End-of-Life Care

Launched in 1996, Promoting Excellence in End-of-Life Care searched for models that worked well in end-of-life care. The initiative's director, Ira Byock, M.D., was an emergency medicine doctor who "understood the importance of translating the practice of palliative care to physicians most on the line to decide about saving or extending life."

Education in Palliative and End-of-Life Care (EPEC)

Education in Palliative and End-of-Life Care (EPEC) was a program developed by the American Medical Association to "change how practicing physicians approached the delivery of care at the end of life." It sought to:

1. develop a curriculum to train practicing physicians, and
2. implement a large-scale "train the trainer" model that could reach all practicing physicians in the US by relying on an ever-growing pyramid of successive training.

Moving Forward: Building the Field of Palliative Care

In addition to these three grants, RWJF developed a strategy based largely on recommendations offered in the 1997 Institute of Medicine (now National Academy of Medicine) report, *Approaching Death: Improving Care at the End of Life* (Field and Cassel, 1997). The report followed the SUPPORT findings and analyzed several aspects of care at the end of life; it became instrumental for RWJF and others, such as Open Society Institute's Project on Death in America. Ultimately, RWJF "selected three main objectives that addressed many elements in the [IOM] report:

1. To improve the knowledge and capacity of health care professionals and others to care for the dying
2. To improve the institutional environment in health care institutions and in public policies and regulatory apparatus to enable better care of the dying
3. To engage the public and professions in efforts to improve end-of-life care

Approaching Death: Improving Care at the End of Life became the touchstone for much of the work later supported by the Foundation. The study came to frame the clinical and related system issues for the field, and laid the footprint for a more evolved field. However, the IOM report did not specify strategies to create the change envisioned."

Palliative care thus became the clear focus of RWJF's work. Given that it was a relatively underdeveloped area, the Foundation identified the need to establish a "knowledge field" with the following elements:

- "Shared identity and sense of mission among the members
- Leaders
- Systems for training, education
- Credentialing
- Locations to practice
- Knowledge base
- Quality standards
- Public policy support and funding"

Medical Education Reform

The Foundation's grantmaking, which revolved around supporting the various elements of this knowledge field, had several important successes:

- With support from OSI's Project on Death in America, the American Board of Hospice and Palliative Medicine (ABHPM) "helped hospice and palliative medicine achieve recognition as a medical subspecialty in near record time." For this achievement, RWJF "supported the Accreditation Council for Graduate Medical Education (ACGME) to develop standards for post-residency fellowship programs in hospice and palliative care and then accredit programs as they came on line" and "PDIA, on the other hand, provided support during this period for ABHPM to take a leadership role in formalizing recognition of hospice and palliative medicine."
- The Foundation supported reform efforts in nurses' education to ensure that they, too, were adequately trained to provide end-of-life care. These grants supported teaching, licensure programs, and certification initiatives to encourage nurses to develop expertise in the field.
- RWJF research grants "gave emerging leaders in palliative care the chance to publish, earn tenure and garner respect and influence in the world of academic medicine."
- Standards, particularly in medicine, play a powerful role in shaping the field; RWJF invested in a series of projects to help the field define and achieve consensus on the elements of quality, and to establish methods to measure whether standards are met.

Redefining Palliative Care and Investing in Hospitals

One of RWJF's most important contributions to the field was the "breakthrough idea" that patients could receive palliative *and* curative care, which ran counter to the then-common perception of palliative care as "giving up" on a patient's life to focus on a good death. Additionally, the Foundation sought to distinguish palliative from hospice care and expand the target population and the market for palliative care.

The Foundation saw an important opportunity in investing in hospitals and hospital-based palliative care programs—stable organizations that were well-situated to address the issue. In 1999, RWJF made a grant to establish the Center to Advance Palliative Care (CAPC), "a national resource center to impart skills, build leadership and create the momentum to grow hospital-based palliative care programs throughout the nation." In time, this initiative would train almost half of all hospital palliative care programs in the country.

Community Engagement

Another (smaller) area of RWJF's grantmaking, Community-State Partnerships to Improve End-of-Life Care and Last Acts initiatives, worked to engage the public in a local, regional, and national conversation around death and end-of-life care preferences. These efforts included:

- Through Last Acts and Community-State Partnerships, the Foundation supported hundreds of advocates and "provided them with information and resources, and then let them take the lead on issues they wanted to address in their own states and communities. The Foundation saw the local and state groups as a resource to both educate the public about their choices and use them to rally for changes in medical care and policy reform."
- As part of Community-State Partnerships to Improve End-of-Life Care, "the more common approaches were efforts to improve training and provide continuing training opportunities for health care professionals; influence changes in policies and procedures at health care facilities; increase consumer knowledge, awareness and advocacy; engage clergy and faith communities in end-of-life care delivery; and reform care with more broad-based end-of-life policies. This program aided five states in making considerable strides to improve end-of-life care and help others progress their agendas"
- Another of RWJF's major public engagement efforts was the four-part series "On Our Own Terms: Moyers on Dying", which aired in September 2000 on PBS. The program attracted 16 million viewers and ignited a yearlong campaign to engage viewers and communities in a productive dialogue to address dying and end of life care.

“State of the Field Today”

The report identifies a series of metrics showing the differences in the palliative care field since the SUPPORT findings were released. It concludes that “today” (in 2011):

- There is overall approval of palliative care as a medical subspecialty,
- There are more medical professionals trained to perform in this field,
- There is greater focus on palliative care in medical education programs across the board,
- There has been a rapid expansion of clinical training and practice locations,
- There are evolving quality standards for palliative care practices, and
- There is an emergence of networks for practitioners and researchers.

The report does not analyze improvements made in the area of community engagement and public outreach.

Conclusions on RWJF’s Work

The report identifies the following accomplishments of the Foundation’s work in the end-of-life care field. Robert Wood Johnson Foundation:

1. “Created a call to action that mobilized powerful voices in the medical community.
2. Supported the creation of an agenda for the field and by the field.
3. Reframed the problem from end-of-life to palliative care, creating demand to provide care “upstream.”
4. Created a linked strategy of “pulls” that developed demand for palliative care training and research.
5. Built the base and disseminated highly useful knowledge that could be applied immediately and build the audience for more knowledge.
6. Fostered the development (and employment) of a highly influential network of leaders who emerged from the PDIA Faculty Scholars Program and went on to influence medicine in substantial ways.
7. Supported an institutional base for delivering palliative care that was financially viable, acceptable to hospital leadership, physicians, patients and families and therefore could be taken to scale.
8. Built into existing frameworks the standards and measures to track the performance of key systems, including those certifying or regulating medical education, hospitals and the training of graduate physicians and thereby creating and reinforcing desired change.”

Finally, one of RWJF’s regrets was that it phased out its end-of-life grantmaking at a time that happened to coincide with the closure of OSI’s Project on Death in America. Realizing the negative effect their simultaneous exit from the field could have on

grantees, RWJF mitigated its “mistake” by making a “challenge grant to continue to foster hospice and palliative care that eased the transition.” The foundation urges donors to be aware of their role and timing relative to others in the same grantmaking field.

Open Society Institute, “Transforming the Culture of Dying: The Project on Death in America, October 1994 to December 2003”

http://www.opensocietyfoundations.org/sites/default/files/a_transforming.pdf

Founded in 1993 by investor and philanthropist George Soros, the Open Society Foundation (OSF)—formerly the Open Society Institute—is a private foundation based in New York City. In 1994, OSF initiated the Project on Death in America (PDIA), which would spend nine years distributing \$45 million to address seven priority areas in end-of-life care. More than half these funds went to professional development initiatives for medical professionals and social workers. The project recognized that faculty members and clinicians would spearhead meaningful changes around end-of-life care, helping to achieve the project’s goal of transforming the experience of dying in the United States. The Project on Death in America’s advisory board was led by Kathleen Foley, M.D., a neurologist and chief of the pain and palliative care service at Memorial Sloan-Kettering Cancer Center in New York City.

In 2002, George Soros announced the reorganization of his Foundation’s network, effectively ending PDIA. Though the project had made significant inroads in the field of palliative care, the significant work still to be done would require continued philanthropic support. Upon completing PDIA’s grantmaking at the end of 2003, OSF commissioned a report to inform others about the strategies and lessons learned from the nine-year Project on Death in America. The beginning of the publication outlines the three eras in PDIA’s grantmaking, but it focuses mostly on direct recommendations for future funders so that the legacy of PDIA’s work may continue.

Key Grantmaking Themes

Over nearly a decade, OSF initiated three stages of funding for the Project on Death in America. In the first era, 1994 through 1997, OSF identified seven priority areas for funding, and focused on changing the culture of medicine from inside the hospitals and nursing homes where approximately 70 percent of Americans die. As a result, professional development was fundamental to the project’s grantmaking efforts, both during this period and through the final grants in 2003. PDIA initiated professional scholarship and leadership programs such as the Faculty Scholars Program and the Social Work Leadership Development Awards, which became important and longstanding elements of PDIA’s work.

During its second phase (the late-1990s), the project expanded its grantmaking to support community arts and education, as well as address the challenges that underserved communities face. The arts and humanities became important media through which individuals and communities could express experiences of illness, death, and grief to facilitate conversation and reflection. PDIA also funded interfaith,

community-based, and school-based programs that supported individuals and groups in the bereavement process. Finally, PDIA challenged the legal and economic barriers that hindered quality end-of-life treatment for vulnerable populations, or groups likely marginalized by the palliative care system (including children, the elderly, non-English speakers, the incarcerated, the homeless, members of racial or cultural minorities, and people with physical or developmental disabilities).

In its final stage of grantmaking (2000 through 2003), OSF focused on institutionalizing change by “building a sustainable field of palliative care, with the sufficient infrastructure and leadership to dismantle the barriers that still kept people from receiving excellent care.” They did this by forging partnerships with other funders, including the Emily Davie and Joseph S. Kornfeld Foundation. PDIA’s other collaborations are discussed in the “Partnerships” section below.

Grantee Highlights

OSF no longer lists all of PDIA’s grants on its website, but the report highlights select grantees. It also gives grant details for the first three years of PDIA’s funding. Between 1994 and 1997, the Project on Death in America received more than 2,000 grant requests over four grant cycles and funded 122 projects. Grants ranged from \$5,000 to \$400,000 and supported numerous disciplines contributing to end-of-life issues, from the medical to the philosophical to the political. Though metrics throughout the project’s lifespan are unknown, the report does detail some final grants given in 2003: a \$1.2 million grant awarded to the American Academy of Hospice and Palliative Medicine, and five other grants of \$200,000 or \$100,000. Over nine years, PDIA granted \$45 million, more than half of which went to professional development programs for medical professionals and social workers.

At the end of the report, PDIA highlights past grantees in the context of its grantmaking recommendations to future funders. These organizations can be found in the “Findings” section of this summary.

Partnerships

From its outset, PDIA fostered cooperation and collaboration among professionals across various medical, political, and philanthropic fields. In 1995, PDIA, along with the Nathan Cummings Foundation, the Robert Wood Johnson Foundation, the Rockefeller Family Office, and the Commonwealth Fund, formed Grantmakers Concerned with Care at the End of Life. The coalition was meant to expand funding partnerships and to be a resource for other foundations hoping to support end-of-life care. However, it does not appear that this association outlasted the work of PDIA.

In its last stage of funding between 2001 and 2003, PDIA joined forces with the Emily Davie and Joseph S. Kornfeld Foundation to collaboratively grant almost \$2 million to

several palliative care fellowship programs across the country. Palliative care continues to be an important issue for the Foundation.

Findings

The advisory board found that the greatest barriers to quality end-of-life care included inadequate training, weak institutional commitment to end-of-life care, the absence of appropriate funding structures, a lack of quality measures, and major gaps in the research base. However, very little of the over 60-page report discusses the broader obstacles affecting end-of-life care and policy in significant detail, and instead, nearly two-thirds of the document focuses on PDIA's grantmaking. Particular attention is devoted to its exit strategy in 2003 as well as its recommendations for future funders. PDIA uses the examples of its past grants to support its calls for future endowment in these same areas.

Recommendations

In its concluding section on grantmaking strategies and recommendations to funders, PDIA outlines five areas of impact in the field of end-of-life and palliative care:

- Public Engagement
- Professional Education
- Research
- Clinical Care
- Public Policy

These topics represent opportunities for maximum leverage, "where even modest philanthropic investment will yield significant impact." At the end of each section, PDIA provides several examples of grants it made to further these needs, perhaps implying that other foundations should continue to support these organizations or identify others with similar objectives.

Public Engagement

"PDIA promoted the effective use of education and the media to increase discussion of dying, death, and bereavement. It supported strategies for informing the public about programs available to provide a range of support services at the end of life. PDIA also advanced strategies to address the needs of special populations." Key examples of PDIA grants and funding initiatives include the Medicare Rights Center, the largest independent source of Medicare information and assistance in the US, which PDIA funded from 1996 through 2000; the American Pain Foundation, a national nonprofit dedicated solely to meeting the needs of people in pain; the PDIA Media Resource Center, through which PDIA worked with newspaper journalists, book authors, magazine writers, investigative reporters, documentarians, television and radio

producers, and newsletter and industry-publication editors to encourage their participation in addressing the culture and experience of dying in America; the American Hospice Foundation's Grief at School Program, which offers workshops to prepare schoolteachers, counselors, psychologists, nurses, and social workers to help grieving children in the classroom and in after-school programs; and the Arts and Humanities Initiative, which supported 15 grantees who produced books, documentary films, performances, radio productions, and art exhibits.

Professional Education

Noting that less than 0.1 percent of medical school faculty in the US specialized in palliative care, PDIA made significant investments in professional education. They believed that "every grant made to support palliative care education for health professionals has a direct and immediate impact on care for dying patients and their loved ones." In its twelve recommendations for further grantmaking in this arena, PDIA stresses the importance of professional development opportunities for doctors, nurses, and social workers, as well as the need for palliative education in other clinical settings such as nursing homes, cancer centers, rural communities, and prisons. It points to the Faculty Scholars Program and the Funders Consortium to Advance Palliative Medicine as key examples of this type of grantmaking.

Research

In order for palliative care to grow as an accredited medical subspecialty and become the model for good clinical practice, research is key. Thus, PDIA urges future grantmakers to fund research in all disciplines, for adults and children, concerning a broad range of topics that could impact end-of-life care, including pain and symptom management, communication, and ethics and decision making, among many others. Furthermore, the project suggests that concerned funders support centers and sponsor conferences where research can excel and be shared. PDIA mentions the Institute of Medicine (now the National Academy of Medicine) as a seminal grantee in the field of end-of-life research, and also advocates for the increased support of grief research.

Clinical Care

In its clinical care recommendations, PDIA highlights the need for sustained palliative care training and resources in the various clinical atmospheres as mentioned above. It mentions its work with the United Hospital Fund to launch a Community-Oriented Palliative Care Initiative, a three-year effort to develop comprehensive approaches to end-of-life care. Some of PDIA's other grantees in this arena included the Education Development Center, Inc., which worked to improve pediatric palliative care; the Initiative to Improve Palliative Care in the African American Community; and a joint effort with the OSF Center on Crime, Communities, and Culture to address the issue of caring for those approaching death in prisons and jails.

Public Policy

In the realm of public policy, the project echoes some of its earlier proposals. It advocates funding research and evaluation programs that can inform local, state, and federal public servants in their political decisions. Policymakers at all levels might also learn from palliative care clinicians and researchers, strong grassroots coalitions, and bereaved family members. Moreover, PDIA endorses the support of partnerships among disability groups, caregiver groups, advocates for senior citizens, and community groups, among other stakeholders working to improve end-of-life care. PDIA supported the University of Wisconsin Medical School's efforts to address the barriers to availability for opioids for pain relief. Another PDIA grantee in this field was Americans for Better Care of the Dying, a nonprofit organization dedicated reforming pain management, financial reimbursement systems, enhanced continuity of care, support for family caregivers, and changes in public policy.

The Dartmouth Atlas Project

Based out of the Dartmouth Institute for Health Policy and Clinical Practice, the Dartmouth Atlas Project has used Medicare data from the past 20 years to study variations in how medical resources are distributed and used around the US. It examines a number of "Key Issues", including End-of-Life Care, from which several reports have emerged (including those summarized below). The project seeks to understand what variables account for differences in the care that is provided to patients across the country.

Although not exclusive to the Atlas Project, important findings include the assertion that more care is not better care—a point highlighted throughout end-of-life care literature. Patients, families, and doctors in higher-spending regions providing more aggressive end-of-life care do not report more satisfaction, better care, or greater quality of life during patients' last days. The Atlas Project's reports consistently highlight that a main barrier to improved end-of-life care is the poorly understood role that supply of care plays on how much care is eventually delivered, regardless of patient preferences.

The Dartmouth Atlas Project's work on end-of-life research has been funded in part by the Robert Wood Johnson Foundation. Below are summaries of several relevant reports from the Project.

**Wennberg, J. E., Fisher, E. S., Goodman, D. C., & Skinner, J. S. (2008).
Tracking the Care of Patients with Severe Chronic Illness-The
Dartmouth Atlas of Health Care 2008.**

This Dartmouth Atlas Project report studied the links between geography, supply of care, and patient preferences to understand whether or not critically ill patients are getting the kind and the level of end-of-life care they want and need. The goal was to “disentangle” what the authors call “unwarranted variation,” or the variation in care observed throughout the country that cannot be explained “on the basis of illness, patient characteristics or preferences, or the dictates of evidence-based medicine.” This “unwarranted” variation was observed in the 2006 version of the Dartmouth Atlas, and was the main driver behind this 2008 follow-up study.

The authors show that the use of supply-sensitive services (services where the supply of care has a major influence on the rate of use) for treating the chronically ill during their last two years of life varies dramatically across the country, and accounts for a significant portion of Medicare spending. They find that the local supply of medical resources per capita varies widely, and this variation directly affects how much care is used to treat patients at the end of life.

The report focuses on supply-sensitive care delivered to chronically ill patients during their last two years of life, analyzing Medicare spending on inpatient care as well as ambulatory care expenses (which include skilled nursing care, long-term care, home health care, and hospice care). While the analysis correlates level of supply in a hospital with the amount of care given, it does not find that more supply, and therefore more care, results in better care and outcomes. Although certain hospitals spend significantly more money and provide more care, their patients often show worse outcomes than patients in hospitals with fewer care resources. Physicians in regions with the most care available (ICU beds, palliative care specialists, etc.) will deliver more aggressive end-of-life care despite patient needs. The clinical justification for this behavior is the assumption that more, and more aggressive “rescue”, care is better, but challenging this assumption yields important implications for changing how care is distributed and administered. Physicians, the study suggest, “adapt their practice styles to the resources available, but they do so subliminally, in ways that even they are unaware of.”

The authors conclude with the following recommendations:

1. Establish “science-based, cost-effective, and coordinated management of chronic illness through care that is also sensitive to patient preferences and supported by adequate infrastructure.”
2. “Adequate infrastructure” includes the personnel and technology that support both guiding and monitoring quality and efficiency.
3. The resulting health care infrastructure should in time aim to ensure that Medicare reimbursements to care providers are based on these measures of quality and efficiency.

**Fisher, E. S., Esty, A. R., Chang, C. H., & Goodman, D. C. (2011).
Trends and Variation in End-of-Life Care for Medicare
Beneficiaries With Severe Chronic Illness.**

http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf

This report builds on previous Dartmouth Atlas research correlating level of supply with level of care and practice style of clinicians and health systems to highlight major trends in end-of-life care between 2003 and 2007.

By comparing Medicare patient data from 2003 and 2007, and adjusting for differences in age, sex, race, and illness, the authors find that between those years and across most regions of the country there was a decrease in:

- the percentage of chronically ill Medicare patients dying in hospitals
- the average number of days they spent in the hospital before deaths
- the percentage of deaths with a stay in intensive care units

The report's main goal, though, is to highlight the increases in other important indicators, such as:

- the number of ICU days in the last six months of life
- the amount of physician labor used per patient during their last two years of life
- the percentage of patients who saw more than 10 physicians during their last six months of life
- The percentage of patients making use of hospice care

The authors attribute regional variation in end-of-life care intensity to the “supply-sensitive” nature of this care (local supply of medical resources is a key factor in determining how much care patients receive). They note that while a smaller percentage of patients died in the hospital as a whole, hospitalized patients spent more days in the ICU and received more care than before, though there were sharp differences in these trends across regions.

On average, the use of hospitals or ICUs as a site of care does not lead to better patient outcomes, so the supply-sensitive care approach is potentially both misguided and unnecessarily expensive. The authors hope this and other studies will highlight the importance of improving care practices, both to improve patients' quality of life and to eliminate superfluous expenditures.

The report concludes that systems are important: the kind and intensity of care that a patient receives at the end of life is a result of the systems of care in place wherever he or she seeks treatment. There is wide variation across regions and hospitals; providers should seek to ensure that variation in care corresponds to patient preferences and needs, rather than to variability in the supply of care, as the latter is ineffective in providing better care and places an unnecessary financial burden on the healthcare system.

Goodman, D. C. (2013). *Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life*. Dartmouth Institute for Health Policy and Clinical Practice.

http://www.dartmouthatlas.org/downloads/reports/EOL_brief_061213.pdf

This report, funded in part by the Robert Wood Johnson Foundation, follows up on the Project's previous studies of Medicare spending for chronically ill patients at the end of life. Examining Medicare records of more than 1 million deaths among chronically ill patients in both 2007 and 2010, the report reveals that total spending during the last two years of life increased more than 15 percent, from \$60,694 to \$69,947 per patient. The updated data also shows that although spending is higher, Medicare patients spent fewer days in the hospital and received more hospice care in 2010 than in 2007. As in the 2010 report, the Atlas Project concludes that geography is a key determinant of how patients will be treated during their months of life.

A closer look at the data reveals significant changes in care at the end of a patient's life between 2007 and 2010. The use of hospital services in the last six months fell, with a 9.5 percent decrease in hospital days, from 10.9 to 9.9 days, and an 11 percent decrease in deaths in hospital, from 28.1 percent to 25 percent of deaths. The percentage of patients enrolled in hospice increased from 41.9 percent to 47.5 percent, and the average days spent in hospice rose 15 percent from 18.3 to 21 days. The number of days patients spent in intensive care units did not change significantly, nor did the number of physician visits. However, physician visits are increasingly divided among a greater number of doctors: 42 percent of patients who died in 2010 saw 10 or more different physicians during the last six months of their lives, compared to 36.1 percent in 2007.

This study also analyzed indicators at academic medical centers across the country, ostensibly the leaders of best, science-based practices. The trends are indeed different from other medical institutions, but in no particular direction. For example, someone dying at New York University's Langone Medical Center will have spent, on average, 19.1 days in the hospital during his or her last 6 months of life; meanwhile, a patient at the Fletcher Allen Health Care in Burlington, Vermont will have spent 8.6 days in the hospital in the same period. As with other medical institutions, there was great regional variability in intensity of care.

The report's main conclusions are:

1. Location is key. Like the Atlas's previous assessments, this report shows that end-of-life care for chronically ill patients varies significantly across regions and hospitals. Although some indicators suggest that more patients are receiving better care that is respectful of their wishes, there are still certain hospitals where patients receive more aggressive and less palliative care. The reason for this difference is not well understood.

2. More care (that is, more days in the hospital or ICU, treatment by more physicians, etc.) is not always associated with better health outcomes, nor is it aligned with the wishes of the patients. Following less intensive and costly care can yield both savings and improvements in patient outcomes and satisfaction.

Atul Gawande, *Being Mortal: Medicine and What Matters in the End*, 2014.

In *Being Mortal*, practicing surgeon and bestselling author Atul Gawande mounts a compelling argument for the importance of talking and thinking about what it means to live and die well. Drawing on his medical background, Gawande begins by illuminating the medical processes involved in end-of-life care. He addresses issues like the importance of geriatric and palliative care using vivid anecdotes featuring real people, real lives, and very real decisions. Gawande establishes early on, after exploring how the medical system has failed several aging patients, that a desperate need exists for geriatric care. While it does not necessarily increase the lifespan of an aging adult (the deterioration of the human body is inevitable), such care dramatically increases patients' quality of life (studies have shown, for example, drastically lowered depression rates in the elderly).

Gawande also discusses the fact that as the national, and even global, population of elderly and dying increases, a solution like a nursing home is inevitable. However, nursing homes were created to address not this social issue, but the medical issue of needing to clear hospital beds: it does not make sense for hospitals to house the elderly for the months or years leading up to their deaths. While nursing homes adequately answer this need, keeping residents safe and as healthy as possible does nothing to address their quality of life. Many question whether the contained, controlled life of a nursing home, bereft of privacy and autonomy, provides a life worth living for the elderly and debilitated. Through interactions with patients and colleagues, Gawande discovers that bringing a spark of life into a nursing home in the form of plants, animals, and children can offer a welcome contrast to residents' predictable routines. He also observes how well some patients respond to assisted living facilities that afford a sense of autonomy by allowing them a locked door and personal license with their schedules. Gawande makes a point, though, of exposing how overused the term has become, and how many facilities that advertise assisted-living do not follow the original model.

The book's final sections shift from discussing medical facilities to contemplating, at a philosophical level, why a spark of life and a sense of autonomy become so important when facing death. Gawande argues that, "the battle of being mortal is the battle to maintain the integrity of one's life—to avoid becoming so diminished or dissipated or subjugated that who you are becomes disconnected from who you were or who you want to be." Modern medicine strives to treat patients, and it generally fails to stop treatment at the cost of the integrity of one's life. Gawande points out that the fear is always doing too little, never too much. Having a conversation about death requires letting go of the fantasy that medical advances might defy the odds and offer a patient 10 more years. While many patients see having that conversation as giving up, it can in fact improve a dying person's quality of life and quality of care dramatically. Once the patient's wishes are prioritized, the end becomes less daunting and depressing. Gawande urges us to face that reality now, before it is too late, to ensure that our last days are not worse than the thought of death itself, and that we can fulfill our dying role of choice.

FRONTLINE's *Being Mortal* documentary, 2015.

<http://www.pbs.org/wgbh/pages/frontline/being-mortal/>

Tom Jennings' and Atul Gawande's new FRONTLINE documentary, also called *Being Mortal*, aired in February 2015, and puts to film Atul Gawande's book of the same name. The film follows real patients and doctors within two separate hospitals as the patients undergo their end-of-life journeys. Jennings explores how doctors can improve the way they help terminal patients prepare for the end. Ultimately, the film reveals how surprisingly hard it is for doctors who do not specialize in palliative care to speak honestly with their patients about the process of dying. Jennings hopes the film will encourage doctors to ponder the potential consequences of their inability to candidly talk about death. Finally, the film hopes to spur conversations within families and communities about how people want to prepare for death and perhaps make it easier for patients and caregivers to prepare for the reality of death.

National Academy of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, 2014.

The National Academy of Medicine (formerly the Institute of Medicine) recently released a report titled “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life” to address many important end-of-life topics. In the consensus report, a committee of experts finds that improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but also contribute to a more sustainable healthcare system. These issues are particularly pressing given the rapidly increasing number of older Americans with some combination of frailty, physical and cognitive disabilities, chronic illness, and functional limitations. The report ultimately finds multiple opportunities for improvement, making recommendations in the areas of care delivery, clinician–patient communication and advance care planning, professional education and development, payment systems and policies, and public engagement and education.

Many patients nearing the end of life visit multiple specialists when they could be seeing a single palliative or hospice care physician, and the report argues that this fragmented care must be addressed for the sake of the patients. A much better option would be integrated, person-centered, family-oriented, and consistently accessible care near the end of life, provided by healthcare delivery organizations and covered by government and private health insurers. The committee finds that a palliative approach typically affords patients and families the highest quality of life for the most time possible. Although palliative care is well established in most large hospitals and professional education programs, the committee identifies the need for greater understanding of the role of palliative care—by both the public and care professionals—as one of the greatest remaining challenges to the delivery of high-quality end-of-life care.

Additionally, many of these same patients cannot face and make decisions in their weakened state, and their current doctors may not know them already. If patients use advanced care planning, they can be assured that their doctors will be aware of their treatment wishes. The advance care planning process can begin at any age or state of health and should center on frequent conversations with family members and care providers. Electronic storage of advance directives, statements of wishes, or other relevant materials holds promise for improving access to and effectiveness of these materials. Furthermore, doctors should not hesitate to send patients who are not already hospitalized to palliative care, as its benefits can help even those not in dire need. Since palliative care is found to be far superior to other forms of treatment for end-of-life patients, the report calls for a revamp of palliative care education in medical and nursing school curricula.

The report also points out some of the policy issues surrounding Medicare, such as the fee-for-service program, which incentivizes the use of additional services that the patient may not always need. NAM recommends a major reorientation of payment

systems to incentivize the integration of medical and social services, the coordination of care across multiple care settings, and the use of advance care planning and shared decision making to better align the services patients receive with their care goals and preferences.

Finally, there is a call for public engagement and education on end-of-life issues, as well as a need to de-stigmatize the conversations around death and dying that are so essential to one's wellbeing. The NAM committee believes a person-centered, family-oriented approach that honors individual preferences and promotes quality of life through the end of life should be a national priority. "Dying in America" provides a comprehensive assessment of the knowledge gaps, structural problems, and financial disincentives that hamper delivery of optimal care, and it makes cross-sectoral recommendations to achieve compassionate, affordable, sustainable, and effective care for all Americans.

CONFERENCES

Given the great potential for collaboration in this field, funders may find it valuable to attend a conference or summit around end-of-life issues. Schedules and programming shift often, but the following incomplete list suggests a few regular events for funders and stakeholders seeking discussion and collaboration:

- California Coalition for Compassionate Care Annual Summit
- Lown Institute Conference
- Center for Practical Bioethics Symposium
- C-TAC Annual Summit
- Grantmakers in Aging Annual Conference
- Association of Health Care Journalists Conference
- American Academy of Hospice and Palliative Medicine Annual Assembly