

Quality of Life Through End-of-Life Care

“This long period of time marking the end of life points up the importance of having care that enhances functioning, enables control, avoids impoverishment, encourages relationships, supports family, assuages pain, respects spiritual growth, and otherwise generally supports having a good life despite the shadow of death. However, our care system does not yet do this well. Pain and fragmentation of care is commonplace, attention to function is unusual, and even recognition of the implacable fact of mortality seems elusive. We all have a stake in this care. All of us will die, and most of us will have a long period of living with our fatal illness. That time is valuable and deserves attention.”¹

This excerpt, from a statement written by a leader in end-of-life research, Dr. Joanne Lynn, was endorsed by more than 40 organizations that work in aging and healthcare. It appeared in the *Journal of the American Geriatrics Society* in 1997 and describes challenges that still face society – challenges that grow as the aging population grows.

While the statement speaks to the experiences of people throughout society, it can't fully describe the suffering that most individual patients, families, and caregivers endure when faced with a chronic condition or a terminal illness. Efficient end-of-life care models have been developed and have been proven effective at addressing this suffering. Indeed, meeting the challenges has less to do with development of interventions than it does with implementing existing ones. It is perplexing that interventions

proven to ease suffering and create efficiency are not more widely implemented.

A physician participating in a recent study that examined end-of-life care expressed his frustration with the situation: “We have a lot to learn . . . we abandon patients and families all day every day – and especially all night every night. It’s the dark night of the soul for most patients who are sick and dying, and we don’t even have a language to express where the needs are.”²

Philanthropy has already played an important role in advancing end-of-life care, but there is much work left to do. The influence and strategic investment of the philanthropic sector is essential to implementing interventions that will ensure our aging communities receive the medical care, comfort, and peace they deserve.

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“My vision is to see a discipline, or a community, or network of providers across settings where we can really link hospice and the rest of the medical system together and create a real continuum of care particularly for elderly patients with advanced illness.”

*Physician,
San Francisco Bay Area²*

“ . . . personal experiences with the deaths of my parents are two of the reasons I established the Project on Death in America – to promote a better understanding of the experiences of dying and bereavement and by doing so help transform the culture surrounding death.”

*George Soros,
Open Society Institute³*

Defining End-of-Life Care

Since the early 1970s, end-of-life care has met the needs of those in their final days through hospice programs. The interdisciplinary care developed and provided through hospice is known as palliative care. It combines medical, nursing, social, psychological, and spiritual care.

There is a movement to offer palliative care to older adults with advanced illnesses that are not at a terminal stage, but who need comprehensive care. Palliative care physicians, Diane Meier and R. Sean Morrison, explained in a 2004 article that, “. . . by 2030, 20 percent of the U.S. population will be over the age of 65 years. For most people, the years after the age of 65 are a time of good health, independence, and integration of a life’s work and experience . . .” but that, “Eventually, most adults will have one or more chronic illnesses with which they will live for years before they die.”⁴

Together, palliative care for advanced illness and hospice programs create a continuum of care that addresses the advanced and terminal illnesses facing our aging population. They provide answers to the call to action published in the Journal of the American Geriatrics Society’s 1997 article for care that “encourages relationships, supports family, assuages pain, respects spiritual growth, and otherwise generally supports having a good life despite the shadow of death.”¹ They provide appropriate care through each stage at the end of life.

A debate currently exists over the precise meaning of the terms end-of-life care and palliative care. There is also debate over whether the terms represent discrete fields of practice. Palliative care has emerged as a medical specialty that is not necessarily hospice or end-of-life focused. The Glossary of Terms in the next column offers some commonly accepted definitions for these and several other related terms.

Glossary of Terms⁵

End-of-Life Care is provided by physicians and other caregivers to patients approaching the end of life. It focuses on comfort, respect for decisions, support for the family, psychological and spiritual treatments, and counseling. Hospice is one type of end-of-life care.

Hospice keeps patients as comfortable as possible by relieving pain and other symptoms, helps them to prepare for a death that follows their wishes and needs, and reassures both the patient and family members by helping them to understand and manage the situation. It can be provided in a clinical or home setting.

Hospice Home Care allows patients to receive most of their care from family members or friends with help and support from a trained hospice team. The team makes house calls to provide medical and nursing care, emotional support, counseling, instruction, and practical help. An aide may also be available to help at home.

Palliative Care targets quality of life for patients with acute conditions, chronic disease, and terminal illnesses. Control of pain and other physical symptoms, and psychological, social, and spiritual problems are addressed. It has traditionally been thought of as separate from curative care, and not delivered in conjunction with it. Today it is often delivered with a curative care component or counterpart.

Medicare Hospice Benefits provide the majority of funds that pay for hospice services. At the time of this publication, the Medicare hospice benefit is controversial because it stipulates that patients who receive it must waive their right to curative care. This is something that many patients are not willing to do, and that doctors often feel is inappropriate.

Three Decades of Progress and a Wealth of Opportunity

Philanthropy has played a critical role in advancing end-of-life care for more than three decades. Since the early 1990s, both the Open Society Institute (OSI) and the Robert Wood Johnson Foundation (RWJF) supported research, development, and implementation of interventions to advance the way our society deals with illness, death, and dying. Over a ten year period they distributed almost \$200 million for end-of-life and palliative care programs. Collectively, OSI and RWJF funded the establishment of programs that continue today, supported the development of models that can be replicated, and offered recommendations for other funders.

In 2004, OSI offered recommendations for funders in the following categories:³

- Improve and provide professional education
- Build the palliative care evidence base
- Improve direct service delivery and clinical care
- Work to inform public policy
- Foster public engagement and education

RWJF's extensive grantmaking was preceded by a study it funded that involved 9,000 critically ill patients. Study findings suggested that even though home care and hospice have grown significantly, most people die in hospitals, often alone and in pain.⁶ Responding to these findings, RWJF funded projects that tested innovative approaches in palliative care targeting cost effectiveness and efficiency in care delivery.

A great need now exists for other philanthropists to build on the work of OSI and RWJF, and to seize the excellent opportunities for impact. Funders in this field can realize substantial returns on investment, with even small grant budgets.

“There’s still a lot of work to be done . . . We don’t have the kind of resources we had before. We’re hoping that other philanthropists . . . will step up to the plate to make sure patients get the kind of care they deserve.”

*Susan Block,
Harvard Medical School⁷*

Grantmaking Opportunities

In its publication, *Transforming the Culture of Dying: The Project on Death in America*, OSI urged, “Any foundation concerned with alleviating human suffering can help improve end-of-life care for patients and their families — regardless of geographic focus, grant size, or funding priority. In the end, every funder has a personal stake in the quality of the end-of-life care system we create.”³ Some of the many issues addressed through end-of-life care are listed below along with examples of related funding opportunities. The first five lend themselves especially well to local, state, or regional level grants, but could be scaled to the parameters of any size grantmaking budget.

More highly trained staff

Training is needed for end-of-life care professionals at every level.

Funding possibilities: *Grants for end-of-life care symposia, seminars, workshops, or lectures to update geriatric healthcare professionals and other service providers.*

Physician, nurse, and social worker training programs

The success of end-of-life programs is significantly enhanced by ongoing training for physicians, nurses, and social workers.

Funding possibilities: *Short-term fellowships to support training in hospice and palliative care for physicians and nurses.*

Key program functions

Small-scale support can ensure that more complete care is provided where patients might otherwise receive the bare minimum.

Funding possibilities: *Funding for programs that train volunteers to be companions for terminally ill patients so that no person dies alone.*

Quality of life

There are many services not considered to be core services that can enhance patient quality of life, but for which there is often no budget allocation.

Funding possibilities: *Quality of life projects for hospice patients like art therapy, pet therapy, and massage therapy.*

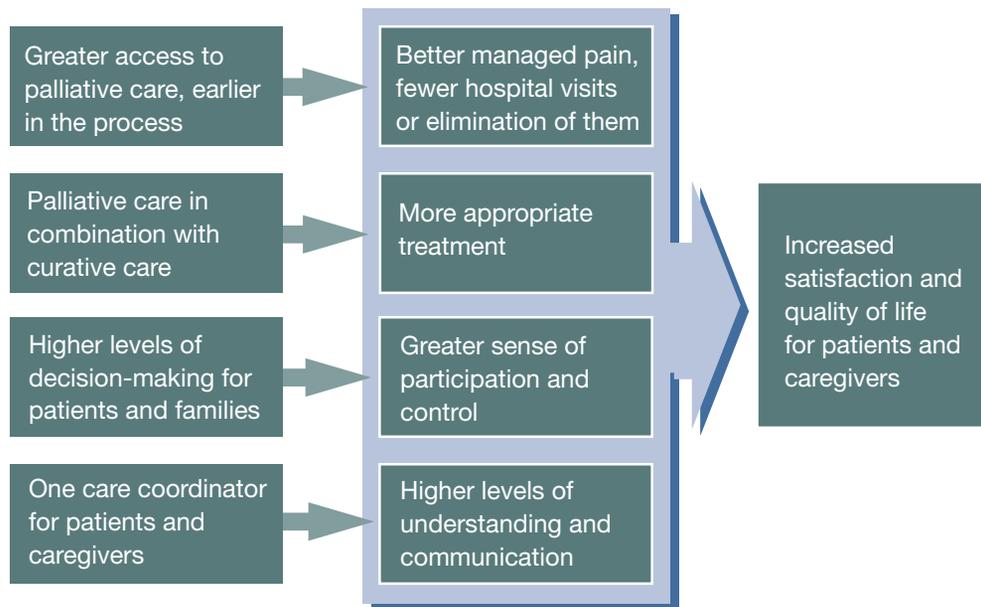
Community education

Those in need of end-of-life services are often unaware of available assistance.

Funding possibilities: *Meetings in senior centers, nursing homes, churches, and assisted living facilities for older adults and families to discuss palliative care, advance directives, and hospice care.*

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Model for Palliative Care Delivery Toward Higher Quality of Life



Based on information from the Open Society Institute's, *Transforming the Culture of Dying: The Projects on Death in America: 1994 to 2003*, (2004); and from the Robert Wood Johnson Foundation's national program, Promoting Excellence in End-of-Life Care, which operated between 1995 and 2003.

The following four issues are represented above in the *Model for Palliative Care Delivery Toward Higher Quality of Life*.

Greater access to care, earlier

Palliative care programs to support those with ongoing chronic illness are still not found in most healthcare settings. Also, hospice care is generally not requested by patients and caregivers — and often is not recommended by doctors — early enough to be as effective as it could be.

Funding possibilities: *Education for doctors, public education, hospice outreach programs, and new palliative care programs.*

Palliative care in combination with curative care

Because of reimbursement policies, many patients are forced to make the difficult choice between palliative and curative care, when both are needed. This has come to be known as the “terrible choice.”

Funding possibilities: *Research that may lead to changes in federal and/or private reimbursement policies, and ongoing development of existing programs that demonstrate the value of combined care.*

Higher levels of decision making for patients and families

Patients and families need clear information about prognoses and care options so they can participate more actively in decision making.

Funding possibilities: *Education for healthcare professionals on how to communicate better with patients and families, and family support and education programs.*

Coordinated care

Interdisciplinary, coordinated care evolved principally through hospice and has been developed extensively. Yet, not enough healthcare professionals have been trained to provide coordinated care.

Funding possibilities: *Programs that train doctors and nurses to provide coordinated palliative care.*

Examples of programs and projects:

- *The Center to Advance Palliative Care provides healthcare professionals with tools, training, and technical assistance to start and sustain palliative care programs in hospitals and other healthcare settings. (www.capc.org)*

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“Patients and families tell us they need information, reliable access to help, and relief from distress so they can live as well as possible with their medical condition. Palliative care is the solution.”

*Diane Meier, M.D.,
Center to Advance
Palliative Care⁸*

- **City of Hope Pain and Palliative Care Resource Center** disseminates information and resources for improving quality of pain management and end-of-life care. (www.cityofhope.org/PRC)
- **Palliative Care Service at the University of California San Francisco** provides care to improve the quality of a person's last phase of life, and also for those who may not be in the last phase, but who are suffering from severe conditions such as heart failure, emphysema, and chronic liver disease. (www.ucsfhealth.org)

Stimulating demand for services

Palliative care experts explain that one of the key items that needs to be addressed is the lack of demand for palliative care. This is due, in part, to a lack of public and professional understanding of how it can be used, and the benefits it brings.

Funding possibilities: Strategic communications for social change, including market research to determine key segments and strategies, and professional training programs for medical and nursing staff.

Examples of programs and projects:

- **On Our Own Terms: Moyers on Dying**, a documentary series based on two years of research led by award-winning journalist Bill Moyers. (www.pbs.org/wnet/onourown/terms)
- **End-of-Life Nursing Education Consortium (ELNEC)** prepares qualified nurse educators to provide end-of-life education for nursing students and practicing nurses. (www.aacn.nche.edu/elnecc/curriculum.htm)

Culturally appropriate care

End-of-life care programs are still not being used by non-white ethnic groups to a significant degree despite recent efforts.

Funding possibilities: Research in culturally competent care, and development of culturally specific programs that include outreach.

Examples of programs and projects:

- **Hospice Minnesota's Opening Doors to Multicultural Communities** program

provides hospice organizations with patient and family centered practices, resources, training opportunities, and multicultural experiences. (www.mnhospice.org)

Spirituality

While spiritual aspects often play an essential role in hospice and palliative care programs, they aren't always understood or addressed. Spirituality is an important area for research and innovative intervention.

Funding possibilities: Training in related communication skills for medical professionals, research and demonstration projects in the area of end-of-life oriented communications and spirituality, development of spiritual outreach programs, and related education for funders.

Examples of programs:

- **The Center for Spirituality, Theology and Health in the Center for Aging** at Duke University supports trans-disciplinary conversation and collaborative research. (www.dukespiritualityandhealth.org)
- **The Bay Area Jewish Healing Center** in collaboration with the **Zen Hospice Project** (www.zenhospice.org), trains and places volunteer companions with end-of-life/hospice patients. (www.jewishhealingcenter.org)

CALL TO ACTION

This publication only begins to explain the compelling case for funding in end-of-life and palliative care. There are extensive resources available that cover every aspect of this topic, including the reasons for supporting related initiatives and the best opportunities for maximizing impact with available grant dollars. The *Recommended Reading and Resources* section on the next page provide a starting point. Please contact Grantmakers In Aging for additional information about funders currently working in the areas of end-of-life and palliative care.

“This movement to improve care at the end of life is consumer driven. Death is the most universal experience of all. We're all going to get there. And we'd better be asking doctors for the care we want.”

*Bill Moyers,
Public Broadcasting System⁹*

Recommended Reading and Resources

- ▶ **Promoting Excellence in End-of-Life Care** website (www.promotingexcellence.org), created by the Robert Wood Johnson Foundation Promoting Excellence in End-of-Life Care program office and provides an array of resources.
- ▶ **National Hospice and Palliative Care Organization** website (www.nhpc.org) contains extensive information and resources.
- ▶ **Sick To Death and Not Going to Take It Anymore!: Reforming Health Care for the Last Years of Life**, by Joanne Lynn, MD, includes facts, concepts, and strategies. It takes into consideration the U.S. healthcare system, which is not set up to handle the masses of people who will be facing a prolonged progressive illness and disability before death.
- ▶ **Transforming the Culture of Dying**, describes what the Open Society Institute learned through its Project on Death in America and provides grantmaking recommendations. This publication can be found on the OSI website at www.soros.org/initiatives/pdia.

Credits

Publisher: Grantmakers In Aging, 2007

Writer: Ned Schaub, MissionWise

Designer: Kristi Kuder, Hold that Thought! Co.

Editorial Advisory Group:

Therese Ellery - Rose Community Foundation, CO

Teri Foster - Children's Memorial Hospital, IL

Marcia Slater Johnston - Harry G. and Charlotte H. Slater Family Fund, WI

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Contact GIA

Grantmakers In Aging
7333 Paragon Road, Suite 220
Dayton, OH 45459
Tel: 937-435-3156
Fax: 937-435-3733
E-mail: info@GIAging.org
www.GIAging.org



Dame Cicely Saunders established St. Christopher's Hospice in England in 1967. It was the world's first purpose-built hospice and was founded on the principles of combining expert pain and symptom relief with holistic care to meet the physical, psychological, and spiritual needs of its patients and those of their family and friends. Dame Cicely died at St. Christopher's Hospice in 2005.

Sources

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⁸ From the Center to Advance Palliative Care-sponsored website, www.getpalliativecare.org

⁹ From the *On Our Own Terms* website, www.pbs.org/wnet/onourown/terms

¹⁰ Photo printed with permission of St. Christopher's Hospice. Text based on information from the Hospice website, www.stchristophers.org.uk

"I did not found hospice. It found me."

*Dame Cicely Saunders,
1918-2005¹⁰*

The EngAGEMENT Initiative, funded by The Atlantic Philanthropies, is a pilot program to introduce new funders to aging through a partnership between Grantmakers In Aging and Regional Associations of Grantmakers.