PALLIATIVE CARE GRANTMAKING

TOOLKIT

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PALLIATIVE CARE GRANTMAKING TOOLKIT

This Palliative Care Grantmaking Toolkit is designed for those new to the field of palliative care grantmaking. In it you'll find ideas for supporting palliative care work in ways that overlap with your foundation's priorities; sources of information about palliative care; information about other grantmakers' work in the field; and advice on how to design your own grantmaking strategy.

The development of this Toolkit was supported by the Collaborative to Advance Funding for Palliative Care (CAFPAC) as a part of its efforts to stimulate and support grantmaking in palliative care.

The Collaborative to Advance Funding for Palliative Care is a growing group of funders from across the U.S that is committed to advancing funding for palliative care. Its steering committee includes the following foundation partners: The Altman Foundation, The Emily Davie and Joseph S. Kornfeld Foundation, The Mayday Fund, The Open Society Institute, The Fan Fox and Leslie R. Samuels Foundation, and Grantmakers In Aging.

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Much of the material in this Toolkit comes directly from publications produced by Grantmakers In Aging and has been used with their permission and by their generosity. *Funding Across the Ages: A Tool Kit* provides a wealth of information for grantmakers that are considering work in the field of aging. *Quality of Life Through End-of-Life Care* looks specifically at palliative care grantmaking for our elders. Both of these publications are available through Grantmakers In Aging (www.giaging.org).

Key definitions have been adapted from the Center to Advance Palliative Care's website for patients and families, www.getpalliativecare.org.

The Toolkit was adapted and written by Ned Schaub and Pam Hagen, of the MissionWise Division of the Comprehensive Health Education Foundation.

INTRODUCTION

How to Use This Toolkit

This Toolkit is intended to help foundation teams, including program staff and trustees, translate the opportunities and challenges of caring for those with a serious, chronic or terminal illness into meaningful grantmaking. It is intended to provide you with some initial ideas for grantmaking that can enhance and complement your current philanthropic goals.

This Toolkit was designed for a wide range of grantmakers, but locally-focused foundations with limited resources to carry out extensive research and planning of a grantmaking strategy will probably find it most useful. The Toolkit sets out straightforward examples for work in palliative care. You may find all of these chapters useful, or you may want to use the Toolkit like a "cook book," using only the sections that are particularly relevant to your foundation's needs or the particular approach that you are taking.

Throughout the Toolkit, you will find:

- Ideas for addressing the needs of those with a serious illness in ways that overlap with your foundation's priorities – and the interests of others in your community
- Advice on how to design your own grantmaking strategy
- Sources of information about palliative care
- Information about other grantmakers with experience funding in palliative care

Building a Community of Palliative Care Grantmakers

Please share this Toolkit with your colleagues, and keep it for your reference. It is not copyrighted, so you can photocopy or excerpt information as you wish. The Collaborative to Advance Funding for Palliative Care is a national network of grantmakers committed to promoting, expanding and strengthening palliative care grantmaking. Philanthropy has already played an important role in advancing palliative 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 that patients, families, and caregivers in our communities receive the medical care, comfort, and peace they deserve.

CHAPTER 1:
ABOUT PALLIATIVE CARE

"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 Care**

Palliative care improves quality of life for patients and their families. The Center to Advance Palliative Care describes palliative care (on its website for patients and families, www.getpalliativecare.com) as follows:

> Palliative care (pronounced pal-lee-uh-tiv) is the medical specialty focused on relief of the pain and other symptoms of serious illness. The goal is to prevent and ease suffering and to offer patients and their families the best possible quality of life.
>
> Palliative care is not dependent on prognosis and is appropriate at any point in an illness. It can be provided at the same time as treatment that is meant to cure you.

Facts About Palliative Care and Palliative Care Grantmaking

• Palliative care is about life and living it fully – even in the face of chronic or terminal illness.

• Palliative care is patient-focused and targets comfort and dignity for every patient.

• Research and powerful stories show us that quality of life for patients of any age – from infants to elders – improves through Palliative Care.

• Palliative care is a proven approach to help address a range of issues at the patient and health care system level – everything from pain management to social justice.

• Palliative care is offered in a range of settings across the spectrum of healthcare and the type of palliative care offered in a particular setting is often tailored to that setting. Some examples are critical care settings, hospital settings, home settings, long-term care settings, and pediatric hospital settings.

• Palliative care grantmakers realize substantial returns on investment, with even small grant budgets.

* Palliative care grantmaking approaches have been developed and documented, so that grantmakers can easily begin working in this area or add to work already done.

Palliative Care: A Brief History

The Beginning of a Movement

Since the early 1970s, palliative care has met the needs of those with serious illness – and those dealing with chronic and terminal illnesses. This interdisciplinary care, first developed and provided through hospice, generally combines medical, nursing, social, psychological, and spiritual care. Over the last two decades a movement has begun to offer palliative care across the spectrum of care, so that this highly effective care can also be offered to those who are not at a terminal stage, but that need such comprehensive care. Palliative care has emerged as a medical specialty that is not necessarily hospice or end-of-life focused – and there is now physician board certification for palliative care. Programs ranging from pediatric palliative care to geriatric palliative care, and from hospital-based palliative care to hospice, now collectively create a continuum of care that addresses the pain and suffering of those at every stage of life.

Reducing Suffering

A growing body of literature describes the suffering that occurs in the U.S. because of care delivery that is not appropriate. Research and demonstration projects in palliative care conducted over the last decade indicate that much of this suffering is not necessary, and that providing more effective and appropriate care can reduce suffering. Alongside the research has been the growth of palliative care as a field, including the training of professionals and the establishment of programs.

The Way Americans Deal with Serious Illness and Death

In the last decade palliative care has taken the hospice model further in addressing the range of issues facing patients, and their families and caregivers; but hospice laid the groundwork for the field, starting with the founding of the first U.S. hospice in the early 1970s and continuing through the establishment of more than 2,400 hospices (National Association for Home Care & Hospice, 2004). Hospice has become an industry, has its own Medicare and Medicaid benefits, and is delivered in a range of manners in public, private, and nonprofit settings. Yet, during those more than 30 years, changes in medical technology and medical culture apart from hospice and palliative care have significantly altered the way Americans deal with serious illness and death.

Experts watching this evolution indicate that there are substantial negative repercussions tied to aggressive medical treatment that prolongs life, while decreasing the quality of that life. They argue that we have lost sight of the balance between extending life and providing for quality of life. They cite absence of education for patients, their caretakers, and families; medical professionals who, though they have extensive medical training, don't know how to deal with

patients and their families in ways that are appropriate; and a lack of organized systems to support patients at such a difficult phase in their lives. Many healthcare professionals, hospices, hospitals, and other organizations have recognized the growing need for models that provide palliative care to a broader group of patients, in ways that are more flexible.

To explore palliative care, its evolution and current state, and to understand the context in which it exists, it is essential to understand the evolution of hospice in the U.S. Palliative care evolved to a large extent out of hospice, yet hospice is now considered by many working in palliative care to be just one type of palliative care. Examples of non-hospice types of palliative care include: palliative care provided to those with a chronic illness, but who are not at the end of life; and palliative care that is provided to those of any age simultaneously with curative care.

On the Differences Between Hospice and Palliative Care

Hospice care is an organized program for delivering palliative care. It has been referred to as the "gold standard" of palliative care in the U.S. Hospice programs in the U.S. have focused on caring for the terminally ill in their own homes. However, a growing number of hospice organizations provide palliative care services earlier in the course of illness through a variety of mechanisms. Palliative care programs, as they are now developing in the U.S., aim to serve patients throughout their illness experience, particularly, although not exclusively, in acute care hospitals and ambulatory outpatient settings.

Medicare has a significant impact on the delivery of hospice care in the U.S. If a hospice program wishes to have its services paid for under the Medicare Hospice Benefit, the hospice program must meet federal regulations. Most hospice programs and their patients and families rely on this payment option. The United States Medicare Hospice Benefit [has limited] care to patients who: 1) Agree to therapy with a palliative intent; 2) Have a life expectancy of less than 6 months if the disease runs its usual course in the judgment of the patient's attending physician and the hospice medical director; and 3) Elect the Medicare Hospice Benefit for coverage of all services related to their terminal illness.

By contrast, developing palliative care programs generally address the physical, psychosocial, and spiritual needs and expectations of patients with life-threatening illnesses at any time during that life-threatening illness—even if life expectancies extend to years. Although the focus intensifies at the end of life, the core issues of relief of suffering and improvement of quality of life are salient throughout the course of the illness.

– From the Center to Advance Palliative Care's *CAPC Manual: How to Establish a Palliative Care Program*, ©2002

Please Note: As of October 2008, information regarding some relevant changes in Medicare reimbursement had been posted to the CAPC website (www.capc.org). Please check the site for details and updates

Increasing Access and Integration of Palliative Care: The National Consensus Project

Much of the thinking on best practices and targeted paradigm shifts in palliative care are well summarized in the following short list of targets, outlined by the National Consensus Project in 2004:

- Pain and symptom control, psychosocial distress, spiritual issues and practical needs are addressed with patient and family throughout the continuum of care.
- Patients and families obtain the information they need in an ongoing and understandable manner, in order to grasp their condition and treatment options. Their values and goals are elicited over time; the benefits and burdens of treatment are regularly reassessed; and the decision-making process about the care plan is sensitive to changes in the patient's condition.
- Genuine coordination of care across settings is ensured through regular and high-quality communication between providers at times of transition or changing needs, and through effective continuity of care that utilizes the techniques of case management.
- Both patient and family are prepared for the dying process and for death, when it is anticipated. Hospice options are explored, opportunities for personal growth are enhanced and bereavement support is available for the family.

World Health Organization Goals for a Palliative Care Policy

A 2004 World Health Organization report (Davies & Higginson, 2004) listed tangible goals for future palliative care policy. Among them:

- Support for families and caregivers in their efforts to care for the patient and to cope with the sense of loss that the illness brings. This might include assistance similar to that often granted to those with maternity and paternity responsibilities.
- Services available on the basis of need in terms of symptoms and problems, and their effectiveness in meeting that need, rather than on the basis of diagnosis.
- Development of palliative care skills in staff working across all settings, especially in pain and symptom control and communication.
- Services more widely and broadly offered and integrated across all health services.
- Public education designed to increase awareness of palliative care issues.

CHAPTER 2: FOUNDATIONS AND PALLIATIVE CARE

***"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 School (Perry, 2005)**

Three Decades of Progress and a Wealth of Opportunity

Philanthropy has played a critical role in advancing palliative care for more than three decades. Palliative care models have been implemented at a number of institutions across the U.S. – through funding provided by private foundations, through innovative financing, and through efforts of individual healthcare providers and professionals. However, while many of these models have been proven to be effective, to a large extent they have not been replicated.

Experts working in the development of palliative care programs and in palliative care advocacy argue that palliative care could enhance the current efforts of many funders, helping them achieve deeper impact in their current focus areas, and that even modest amounts of funding can enable implementation of proven palliative care interventions.

The Work of Two Major Funders and Lessons Learned

Starting in 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 they funded the establishment of programs that continue today, supported the development of models that can be replicated, and offered recommendations for other funders. By the end of its initiatives, the Robert Wood Johnson Foundation had contributed approximately $150 million for palliative care projects -- and the Open Society Institute approximately $45 million (Perry, 2005).

An article published in the Chronicle of Philanthropy in 2005 quoted Susan Block, the chief of the division of psychological oncology and palliative care at Harvard Medical School: "We're hoping that other philanthropists, and particularly the government, will step up to the plate to make sure patients get the kind of care they deserve" (Perry, 2005). The call to action is representative of those of her peers at projects across the U.S. It also represents a real challenge and opportunity for the field of health grantmaking.

Recommendations

There is now a great need 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. In 2004, OSI offered recommendations for funders in the following categories:

- Improvement of professional education
- Provision of professional education
- Building the palliative care evidence base through research
- Improvement of direct service delivery and clinical care
- Work to inform public policy
- Public engagement and education

CHAPTER 3: PALLIATIVE CARE GRANTMAKING OPPORTUNITIES

Any foundation concerned with improving quality of life for patients and their families can make significant impact, even with modest grant budgets — regardless of geographic focus, grant size, or funding priority. 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. Possibilities are also listed that could be conducted on a larger scale.

Training for Healthcare Professionals

Training in palliative care is needed for end-of-life care professionals of every type and at every level (chaplains, doctors, nurses, social workers, etc.). *Funding possibilities include:* 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 include:* Short-term fellowships to support training in hospice and palliative care for physicians and nurses.

Key Program Functions

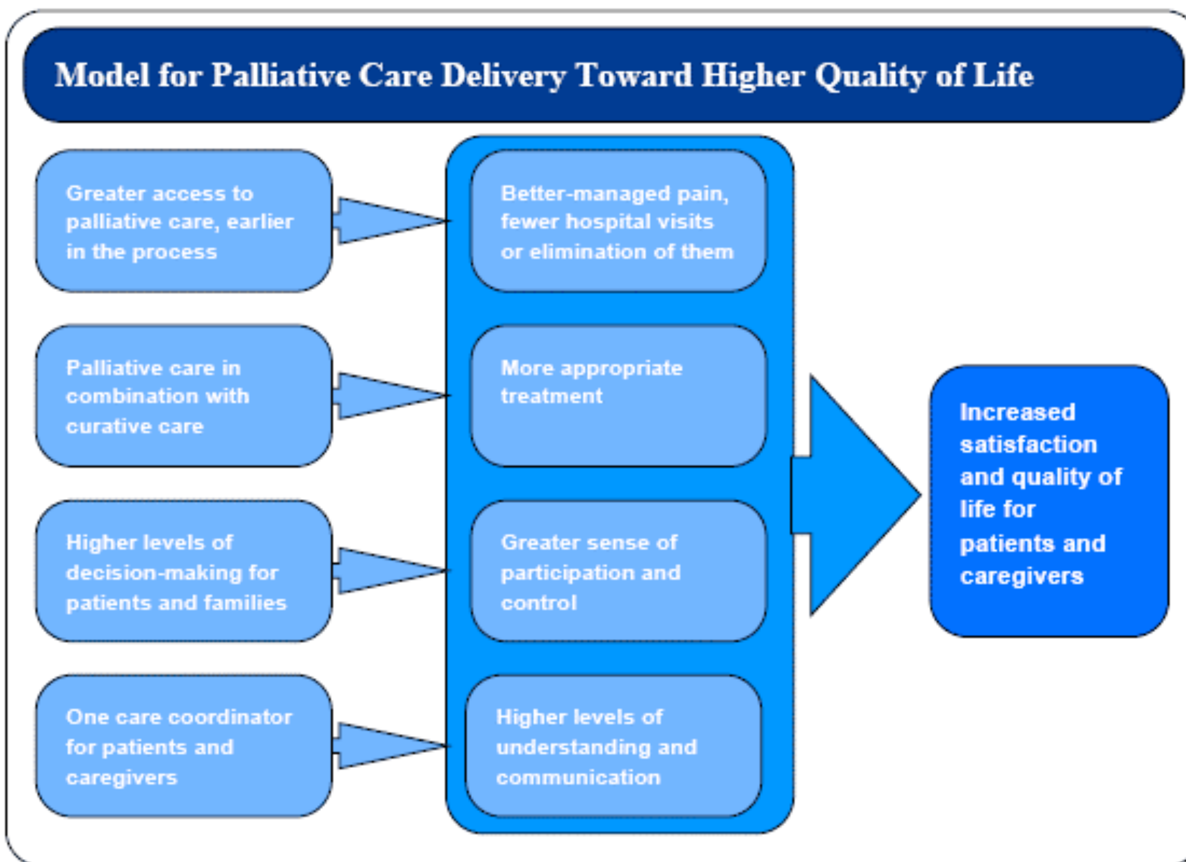
Small scale support can ensure that more complete care is provided where patients might otherwise receive the bare minimum. *Funding possibilities include:* Funding for programs that train volunteers to be companions for terminally ill patients so that no person dies alone.

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 include:* 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 include:* 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.



This model is based on information from materials produced through the palliative care grantmaking work of the Open Society Institute (1994 to 2004) and the Robert Wood Johnson Foundation (1995 to 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 or curative care, when both are needed. This has come to be known as the "terrible choice." *Funding possibilities:* Research that may lead to change in federal and/or private reimbursement policy, and ongoing development of existing programs, demonstrating 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, which evolved principally through hospice, has been developed extensively. Yet not enough healthcare professionals have been trained to provide coordinated care. *Funding possibilities:* Training programs for doctors and nurses that give them the knowledge and skills they need to provide coordinated palliative care.

> ***Examples of Programs and Projects:***
>
> **Center to Advance Palliative Care** (CAPC) 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
>
> **City of Hope Pain and Palliative Care Resource Center** disseminates information and resources for improving quality of pain management and end-of-life care.
> prc.coh.org
>
> **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/adult/special/p/48630.html

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 include: 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/onourownterms
>
> **End-of-Life Nursing Education Consortium** (ELNEC) prepares qualified nurse educators to provide end-of-life education for nursing students/practicing nurses. www.aacn.nche.edu/elnec/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 include: Research in culturally competent care, and development of culturally specific programs that include outreach.

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 include: 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 and Projects:

> **Zen Hospice Project** brings Buddhist teaching together with end-of-life care and training. www.zenhospice.org

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

-- Dame Cicely Saunders, 1918-2005

Dame 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 Saunders died at St. Christopher's Hospice in 2005.

CHAPTER 4:
DEVELOPING YOUR STRATEGY

If you are interested in making grants related to palliative care, we suggest two approaches:

1. Developing a New Strategy. To develop a whole new strategy you will probably want to conduct an "internal scan" of what your foundation already funds to see if there are logical ways to begin, as well as several "external scans" to better understand the needs and funding opportunities in your target community.

2. Building Palliative Care Grantmaking into Existing Strategies and More Modest Approaches. Other funders have begun their grantmaking in palliative care more modestly, or have built palliative care into their existing areas of focus. These smaller steps can give you a feel for the field and let you gain experience in palliative care.

Developing a New Strategy

Some of the suggested steps that follow will be more relevant to your situation than others. These steps are suggested for foundations interested in funding locally; however, you can easily adapt them for use with a regional or national target area.

Developing a strategy for funding usually involves a series of internal and external scans. This work will help you identify and recommend to your team and board areas where your foundation's interests and your target community's needs overlap.

Internal Scan

Step 1. What is your foundation's history?

If your foundation has a clearly stated mission and guidelines, you can quickly identify and understand your funding priorities and begin to seek ways to relate these priorities to palliative care. If there are no guidelines, begin your internal scan by reviewing the grants your foundation has made during the past few years. Look for patterns and trends in your foundation's giving. These questions can guide you:

- Does your foundation fund programs for certain populations, like children, adolescents, older people, or minority populations?
- Does your foundation tend to fund large institutions or small grassroots groups?

- Does your foundation prefer to make grants for direct services, advocacy, public policy, or research?
- Does your foundation focus on particular issues, such as health disparities or social justice?
- How could some of the organizations you have funded incorporate palliative care into their work?

Step 2. What are your foundation's strengths?

Assess your foundation's internal staff and board expertise and other strengths, interests, and connections within the community you serve. If you are connected with a business organization, also consider these areas for its staff and board.

External Scan

Step 1. Consult with your grantmaker colleagues.

Find out who is funding what in palliative care by talking with a few other grantmakers and by using online resources like the Foundation Center (www.foundationcenter.org) and the companion website to this report (www.FundPalCare.org). To identify foundation and corporate funders, contact your Regional Association of Grantmakers, and/or Grantmakers In Aging. See the Resources section of this Toolkit for contact information and other key organizations. Also, ask healthcare organizations in your target community which foundations support them. National grantmaking organizations may be seeking local partners for palliative care-related initiatives in your community. Others will have information about effective methods for addressing the concerns and interests of those needing and working in palliative care.

In addition, government is a significant funder of palliative care, providing funds through Medicare benefits, research grants and other types of funding. By contacting key state agencies and looking at government resources online you can collect information about how government funds palliative care in your target community.

Learn from each funder why they fund what they fund, which palliative care experts and nonprofit organizations are respected, and whom to contact to learn more.

Step 2. Benefit from other organizations' research.

Request copies of evaluations of foundation grantmaking and look at assessments and data that are available through national hospice and palliative care groups and organizations (See the Resources section of this Toolkit). Ask questions such as:

* What palliative care programs exist in the community, who supports and directs them, and who is served by them?
- What capacity to implement or build on palliative care initiatives and programs currently exists in your target community?
- What specific types of palliative care are delivered in the community you are targeting (pediatric palliative care, hospital-based palliative care, hospice, etc.)?
- What are the demographics of your target community? (income levels, ethnic backgrounds, living situations, health status, etc.)

Step 3. Consult with experts in palliative care.

Select three or four directors of nonprofit organizations knowledgeable about palliative care in your community such as a hospice and palliative care organization, a hospital-based palliative care program center – or Grantmakers In Aging, or one of the organizations listed in the Resources section of this Toolkit.

Meet with each organization. Let them know that you are not there to consider making a grant to them at this time, but rather want to learn from them about palliative care so that you can help your foundation determine what types of programs you want to consider funding. Use these meetings as an opportunity to build relationships with the experts in palliative care. They have the potential to help you stay alert to emerging issues and trends, and to identify pressing community needs and funding opportunities.

Ask questions:

- What kinds of services or programs are offered, where, and serving what populations?
- How big is the budget for their programs, what kinds of funding sources support the organization, and which foundations provide funds?
- How many staff are employed and how are volunteers used?
- What other needs of patients and families are they not able to meet?
- What would make the organization more effective?
- How does the organization collaborate or cooperate with other organizations? Which ones?
- What other people and organizations do they recommend you talk with?
- Which other foundations are funding what in palliative care?

- If the executive director could stand back from the organization and consider the big picture—what might the community as a whole do to better respond to patient and family needs?

Analysis and Recommendations

Step 1. Summarize and "hone in" on your special areas of interest.

After analyzing what you have learned, determine where the overlap is between the needs in your target community and the areas likely to be of greatest funding interest to your foundation. Visit a few of these types of programs to see them in action.

Step 2. Prepare to report to your board of directors.

Determine the best way to report to your board of directors what you have learned and what action you recommend. When presenting your strategic recommendations, consider how you can best:

- Clearly state your recommended strategy for funding related to palliative care;
- Provide the rationale for your recommendation;
- Describe the process you used to arrive at your recommendation related to palliative care;
- Explain the benefits to your community and to your foundation of this palliative care funding strategy;
- Explain the risks, or disadvantages of your recommended strategy, if any; and
- Obtain approval to move forward, or if not possible, learn what other information is needed by the board.

Implementation

Step 1. Invite proposals.

If a set of recommendations is approved, modify your guidelines and/or invite organizations to submit proposals that relate to your new palliative care focus.

Step 2. Continue to learn about palliative care issues, trends, and programs that work.

- Ask to be on the mailing lists for the newsletters and reports of organizations.

- Stay in contact with other grantmakers and national and local experts who are good sources of palliative care-related information.
- Join associations of grantmakers that work in palliative care and other professionals in the field, and/or subscribe to their newsletters and other publications.
- Attend local and national conferences on palliative care topics of interest to you.
- Keep talking with experts (and those receiving palliative care, if appropriate and possible) in your community.

PALLIATIVE CARE AND GRANTMAKING RESOURCES

This report is part of a larger effort by advocacy organizations and grantmakers to advance and support the field of palliative care and the patients it serves. The following list includes organizations and initiatives offering additional information and perspectives on palliative care and related grantmaking.

For additional information about palliative care and related grantmaking please visit the companion website to the Palliative Care Grantmaking Snapshot Report, www.FundPalCare.org. In addition to online versions of the Snapshot Report and this Toolkit, it includes an extensive listing of resources.

Open Society Institute Project on Death in America

www.soros.org/resources/articles_publications/publications/report_20041122

The Open Society Institute's Project on Death in America issued a number of recommendations for those considering grantmaking in palliative care. These recommendations relate to how philanthropic support can improve hospital-based palliative care services and promote collaborations of hospice programs, hospitals, and academic medical centers; inform public policy that affects palliative care; support research on the science, ethics, and decision-making related to palliative care; and promote community outreach and education about death and dying, and advance-care planning. Complete details of the recommendations can be found at the Open Society Institute website.

America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals

www.capc.org/reportcard

Provided by the Center to Advance Palliative Care, this national and state-by-state report presents the most accurate estimates to date of the prevalence of hospital palliative care programs in the United States.

Center to Advance Palliative Care

www.capc.org

The Center to Advance Palliative Care (CAPC), a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness, provides healthcare professionals with the tools, training, and technical assistance they need to start and sustain successful palliative care programs in hospitals and other healthcare settings.

GetPalliativeCare.org

www.getpalliativecare.org

Provided by the Center to Advance Palliative Care, GetPalliativeCare.org offers information for people coping with serious, complex illness. Key components of the site include a palliative care directory of hospitals, a definition of palliative care, a definition of pediatric palliative care, and a detailed description of how palliative care differs from hospice care.

Grantmakers In Aging

www.GIAging.org

Grantmakers In Aging (GIA) considers palliative care one of its focus areas and holds issue discussion calls on the subject several times each year. Each call features a palliative care expert and offers the opportunity for GIA members to ask questions and have exchanges with those directly engaged in advancing the field. Palliative care is also included in the GIA annual conference agendas and is the topic of one of its publications.

Institute of Medicine of the National Academies

www.iom.edu

The mission of the Institute of Medicine of the National Academies is “to serve as adviser to the nation to improve health. The Institute provides unbiased, evidence-based, and authoritative information and advice concerning health and science policy to policymakers, professionals, and leaders in every sector of society, and the public at large.” The Institute of Medicine website offers publications and recommendations about palliative care.

National Consensus Project for Quality Palliative Care

www.nationalconsensusproject.org

The National Consensus Project for Quality Palliative Care (NCP) works to further define and underscore the value of palliative care, and to improve the delivery of this care in the United States. The NCP seeks to heighten awareness of palliative care as a treatment option for those with a life-limiting or chronic debilitating illness, condition, or injury. It also seeks to raise public understanding of the growing need for palliative care.

National Hospice and Palliative Care Organization

www.nhpco.org

The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization "is committed to improving end-of-life care and expanding access to hospice care, with the goal of profoundly enhancing quality of life for people dying in America and their loved ones."

National Palliative Care Research Center

www.npcrc.org

The mission of the National Palliative Care Research Center (NPCRC) is to improve care for patients with serious illness and the needs of their families by promoting palliative care research. In partnership with the Center to Advance Palliative Care, the NPCRC will rapidly translate these findings into clinical practice. Specifically, the NPCRC is providing a mechanism to: establish priorities for palliative care research; develop a new generation of researchers in palliative care; and coordinate and support studies focused on improving care for patients and families living with serious illness.

Pediatric Palliative Care

www.getpalliativecare.org/whatis/4

Provided by the Center to Advance Palliative Care, this website is a good starting point to understand how palliative care is designed for children and their families as they make decisions about how best to care for a child with a life-threatening illness.

GLOSSARY

Most of the following terms and definitions have been adapted from the Center to Advance Palliative Care's website www.getpalliativecare.org, which provides information about palliative care to patients and their families.

Advance Directives are written or verbal instructions for a person's care if he/she is unable to make decisions.

Consulting Physician is a doctor with special training or experience who is called in to assist the primary attending physician in matters that need more specialized care.

Coordination of Care is an approach in which all members of the medical team work together to plan for a patient's care in the hospital and for discharge.

Do Not Resuscitate (DNR) Order is a physician's order not to attempt CPR if a patient's heart or breathing stops. The order is written at the request of the patient or family, but it must be signed by a physician to be valid. There are separate versions for home and hospital.

Durable Power of Attorney for Healthcare is a document that designates the person you trust to make medical decisions on your behalf if you are unable.

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.

Healthcare Proxy is similar to a durable power of attorney for healthcare: a document that designates the person you trust to make medical decisions on your behalf if you are unable.

Home Care includes services provided in the home, such as nursing and physical therapy.

Hospice is considered to be a model of quality care. It is a type of palliative care that is delivered to a patient at the end of his/her life. It involves a team-oriented approach to expert medical care, pain management and emotional and spiritual support. The emphasis is on caring, not curing. In most cases hospice care is provided to a patient in his or her own home. It also can be provided in freestanding hospice facilities, hospitals, nursing homes and other long-term care facilities.

Life-Prolonging Treatment includes medical treatments that aim to cure or remedy an illness.

Living Will is a document stating a patient's wishes regarding medical treatments.

Long-Term Care is care that supports patients with chronic impairment for an indefinite period

of time; it is provided in nursing facilities, at home or in the community.

Medicare Hospice Benefits provide the majority of funds that pay for hospice services. The Medicare hospice benefit, at the time of this writing, is controversial because it stipulates that patients who receive it must waive their right to curative care.

Palliate means to relieve the symptoms of a disease or disorder.

Palliative Care is the medical specialty focused on relief of the pain, symptoms and stress of serious illness. The goal is to improve quality of life. Palliative care is appropriate at any point in an illness and can be provided at the same time as curative treatment.

Primary Attending Physician is a patient's main doctor, who coordinates all referrals to specialists.

Resuscitation is similar to CPR, a protocol used when a patient's heart stops beating; it can involve compressions of the chest or electrical stimulation.

Settings, or types of locations, in which palliative care can be delivered vary and the type of palliative care offered in a particular setting is often tailored to that setting. Examples of different settings in which palliative care is offered include: critical care settings, hospital settings, home settings, long-term care settings, pediatric hospital settings, etc.

Subacute Care is short-term care in a nursing facility, usually for physical therapy.

Symptom is a feeling a patient has that indicates a disorder or disease.

"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 System**

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