Putting Palliative Care in Prime Time: A Resource Guide for Health Systems

Together we can save lives and prevent suffering
Palliative care...

- Focuses on **relieving the pain, symptoms, and stress** of a serious illness – whatever the diagnosis.

- The goal is to **improve quality of life** for both the patient and family.

- It’s appropriate at **any age and at any stage** and can be **provided along with curative treatment**.

Definition developed through consumer research commissioned by CAPC with support from the American Cancer Society and the American Cancer Society Cancer Action Network (ACS CAN).
Palliative Care: A Lifeline to Quality of Life

For cancer patients and families, treating the pain, symptoms, and stress of cancer is as important as treating the disease. As such, the Society places a priority on supporting health system efforts to integrate palliative care principles into all facets of the health care delivery system.

Evidence has established the importance of pairing palliative care with oncology treatment in all care settings. It’s essential at any age and any stage to ensure delivery of patient-centered and family-focused quality care throughout cancer treatment and across the continuum of survivorship. Building on the work of specialist palliative teams now in place at the majority of U.S. hospitals, the integration of palliative care in mainstream medicine is achievable and essential to improve the quality of care for all seriously ill adults and children.

Please click on the following links for additional background information about the value of palliative care and the importance of promoting its availability:

- NEJM palliative care Dec 2013 article
- ACS palliative care video
- ACS pediatric palliative care video

The New Paradigm in Health Care Delivery

What is palliative care?

Palliative care is care for adults and children with serious illness, like cancer, that focuses on relieving suffering and improving quality of life for patients and their families, but is not intended to cure the disease itself. It provides patients of any age or disease stage with relief from symptoms, pain, and stress, and should be provided along with curative treatment.

Palliative care treats the whole person beyond the disease, providing patient-centered and family-oriented care that should be available for all seriously ill adults and children from the point of diagnosis, through survivorship, and to the end of life. It should continue in all adult and children’s hospitals, cancer centers, and community care settings.

While palliative care may be delivered by oncology doctors and nurses, they may ask for the help of a specialized team that works with them to provide an extra layer of support addressing the patients’ needs, and helping patients and their families have a voice in realizing their treatment goals. This team-based care includes physicians, nurses, social workers, and others (such as psychosocial counselors, chaplains/spiritual counselors, physician assistants, pharmacists, etc.).
Palliative care teams improve quality and support the primary physician (oncologists, primary care doctors, pediatricians, and others) and the patient by providing:

- **Time** to devote to intensive family meetings and patient/family counseling
- **Expertise** in managing complex physical and emotional symptoms such as pain, shortness of breath, depression, and nausea
- **Communication and support** for resolving family/patient/physician questions concerning goals of care
- **Coordination** of care transitions across health care settings

**Why is palliative care important to cancer patients and survivors?**

Many adults and children are living longer with cancer. But they are also living with the consequences of treatment and its toxicities – including side effects and late effects that can cause significant physical and emotional suffering that last lifetimes. Integrating palliative care early in cancer treatment is essential to manage the symptom burden that otherwise can interfere with daily functioning, make it hard for patients to continue or complete cancer treatment, and keep people from participating in activities that bring joy and meaning to life.

Need for palliative care is not defined by a person’s diagnosis, prognosis, or life expectancy. As recommended by the [Institute of Medicine 2013 Quality Cancer Care Consensus Report](https://www.iom.edu/Reports/2013/Charting-a-New-Course-for-a-Health-System-in-Crisis), “Charting a New Course for a Health System in Crisis”, palliative care should be a routine part of patient care beginning at diagnosis, continuing hand-in-hand with cancer treatment, and lasting throughout long-term survivorship to manage disabling or distressing symptoms and relieve suffering.

**A Rising Trend in Hospitals and Health Systems**

Over the last 10 years, palliative care has been one of the fastest-growing trends in health care. In fact, the prevalence of palliative care in US hospitals with 50 beds or more has nearly **tripled since 2000**, reaching 61% of all hospitals of this size. This is because forward-looking hospitals understand that palliative care is a “triple win” – as beneficial to the patient as it is for the physician as it is for the hospital. A [2011 poll](https://www.regence.org/2011-palliative-care-poll) released by the Regence foundation and National Journal found that an overwhelming majority of doctors (96%) support palliative care.

Several models for implementing palliative care services exist. They include:

- Consultation services provided to inpatient beds placed throughout a hospital
- Dedicated inpatient units
- Outpatient clinics (such as within a cancer center) to help continue care in community settings, including at home.
The **National Consensus Project for Palliative Care** defined optimal palliative care quality program components (updated in 2013) that are endorsed by the Society.

Palliative care is expected to increase as the public becomes more aware of its benefits. But currently, seven out of ten consumers don’t know about palliative care. Moreover, many clinicians misunderstand it. The Society and its advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN) are working with CAPC and other partners to help raise palliative care awareness by giving people the words to use to get the care they need. Please click on the following links to view two Society brochures that explain palliative care for patients and families:

- Society palliative care brochure
- Society pediatric palliative care brochure

**Research provides solid evidentiary foundation**

The following studies demonstrate how palliative care benefits patients, families, and health systems:

- **Improves clinical outcomes**: A [2010 clinical study](#) of 151 lung cancer patients published in the *New England Journal of Medicine* showed that providing palliative care early and alongside usual cancer treatment delivered reduced symptoms, better patient quality of life, and *nearly three months longer patient survival time* than providing usual cancer care alone. (Temel NEJM 2010)

- **Delivers better bottom line**:
  - A [2011 study](#) of four New York state hospitals showed palliative care consultation saved an average of $6900 per admission. Savings of approximately $2600 per admission were seen for palliative care patients discharged from the ICU, and patients receiving palliative care spent on average 3.6 fewer days in intensive care. (Morrison Health Affairs 2011)
  - An earlier [2008 study](#) of eight diverse hospitals showed that on average, palliative care consultation is associated with reductions of $1700 per admission for live discharges and reductions of $4900 per admission for patients who died in the hospital. This translates to savings of more than $1.3 million for a 300 bed community hospital and more than $2.5 million for the average academic medical center. (Morrison Arch Intern Med 2008)

Through an innovative partnership with the **National Palliative Care Research Center** (NPCRC) initiated in 2007, the Society has invested millions of dollars in extramural grants support and mentoring for palliative care and symptom management research. Click on this link to find information about [how to apply for Society research grant](#).
The Society and NPCRC bring our grantees together each year with leaders in the field for the “Kathleen Foley Palliative Care Research Retreat and Symposium” – efforts that are building the community of palliative care researchers and important collaborative projects among them. NPCRC’s Director, Dr. Sean Morrison, is a Society-supported Clinical Research Professor. The Society also recognizes outstanding pioneers in advancing the palliative care field through its annual “Pathfinder in Palliative Care Award.”

Recent Quality Improvement Initiatives Promoting Palliative Care

The groundswell of evidence showing the benefits of palliative care also spurred a number of recent quality improvement initiatives featuring palliative care from professional organizations and institutional accrediting bodies, including:

- **American Society of Clinical Oncology** (ASCO) provisional clinical opinion for integrating palliative care with oncology in all patients presenting with high symptom burden and/or metastatic cancer

- **The Commission on Cancer** patient centered care standards include a clinical requirement (standard 2.4) for palliative care services in cancer centers either on site or by referral

- **National Cancer Comprehensive Network** (NCCN) palliative care clinical practice guidelines in oncology

- **The Joint Commission** hospital advanced certification in palliative care program

- **The National Quality Forum** endorsed 12 new palliative care quality measures

How is palliative care paid for?

Hospitals bill for inpatient days under traditional Medicare/Medicaid or commercial insurance. Physicians (and advance practice nurses in some states) bill for palliative care consultation services under Medicare Part B and commercial insurance. But this billing revenue cannot match the program costs because the clinical work of palliative care is so time-intensive. In many cases, hospitals fill the gap with philanthropic dollars as a significant contributor to the palliative care services financial plan. In addition, hospitals contribute direct funds to support palliative care programs staff, typically providing 50% or more of overall program funding.

Studies have shown this investment will be amply repaid through cost avoidance – specifically through reduction in direct costs resulting from palliative care’s ability to clarify goals and reduce unnecessary ICU days, pharmaceuticals, and x-ray and laboratory costs. The typical return on investment is between two and three dollars saved for every one dollar invested in program costs. Key studies demonstrating cost
savings attributed to palliative care services are summarized above and in the appendix handout.

CAPC has produced a helpful payer-provider partnership toolkit as a reference guide for organizations that lead the financing of health care (including commercial insurers, self-funded employers, and federal and state government agencies) and for providers working in shared risk arrangements.

### Palliative Care: What's in a name?

Using consistent and clear messages to explain palliative care really matters. A 2011 national poll commissioned by CAPC, the Society, and ACS CAN revealed that 7 in 10 Americans are “not at all knowledgeable” about palliative care. Yet an overwhelming majority of people polled (92%) said that they would likely consider palliative care for themselves or their loved ones and believe it should be accessible in our nation’s hospitals when it was explained using these key messages:

- Palliative care helps to provide the best possible quality of life for patients and their families.
- Palliative care helps patients and families manage the pain, symptoms, and stress of serious illness.
- Palliative care is a partnership of patient, medical specialists, and family.
- Palliative care provides an extra layer of support for families and patients with serious illness.
- Palliative care is appropriate at any age and at any stage of a serious illness and can be provided along with curative treatment.

Ninety-two percent also said they believe patients should have access to this type of care at hospitals nationwide. While palliative care is a relative unknown among consumers, many providers still associate palliative care with terminal prognosis and believe it becomes useful only near the very end of life. These misconceptions associating palliative care with “giving up hope” or hospice, particularly among disease specialties, remain one of the biggest barriers that keep patients and families from accessing the benefits of palliative care.

Some studies, particularly in oncology, have suggested that changing the name to “supportive care” might help encourage earlier palliative care referrals. But with the clear scientific evidence establishing the importance of early palliative care and the consumer research findings and messaging now available, multiple thought leaders have cautioned against any such name change because it risks adding to the ambiguity and confusion rather than resolving it. Emphasizing that improved communication is essential to appropriate and timely engagement with palliative care services, the American Cancer Society, Institute of Medicine, and several professional organizations, including the American Society of Clinical Oncology, now use the term “palliative care” consistently in their own reports and quality care guidance documents.
Advancing a QOL Public Policy Advocacy Agenda

The Society’s research investment and partnership with NPCRC & CAPC also inspired ACS CAN’s Quality of Life advocacy agenda featuring federal and state legislation, an ad campaign, and the Patient QOL Coalition which convenes multiple national organization members focused on promoting palliative care research, workforce, and access for all seriously ill adults and children. A key message of the QOL advocacy campaign emphasizes the role of palliative care in “treating the person beyond the disease.” ACS CAN’s annual How Do You Measure Up report includes in its quality of life section, content evaluating states’ palliative care and pain public policy landscape, offering a handy reference tool advocates and alliances can use to coordinate action.

Ads from ACS CAN QOL Campaign

ACS CAN also continues to advocate for balanced pain policies in partnership with the State Pain Policy Advocacy Network (SPPAN) and others. An overview of important pain public policy issues affecting patient care is provided in this 2014 article: Efforts to control prescription drug abuse: Why clinicians should be concerned and take action.
Partnering to advance shared quality care objectives

As hospital uptake continues to rise, bringing palliative care services into the community is another essential area for strategic action to ensure these services are available in all settings where adults and children with cancer receive care.

Society health system account managers in your community are prepared to offer information and dedicated support for your institution’s palliative care integration efforts. This includes providing direct and customized assistance in identifying available resources most relevant and helpful for achieving your institution’s particular objectives for delivering optimal patient-centered and family-oriented cancer care.

An institution’s quality care and palliative care objectives may include one or more of the following:

- **Symptom Management**: Clinicians communicate frequently and regularly with cancer patients, survivors, and families about pain, symptoms, and distress, assessing these and other quality of life concerns and needs as part of disease-directed clinical encounters. And provide services to address those needs either directly and/or through referral for palliative care consultation.

- **Shared Decision-making**: Clinicians communicate regularly with patients, survivors, and families about what’s important to them in terms of their quality of life to promote informed shared-decision making and goal-directed care that ensures treatment decisions and care transitions across the continuum align with individual patient and family values.

- **Quality Improvement**: Institution designates palliative care as an integral part of quality cancer care with specific quality of life-focused measures in place (e.g., for pain, symptoms, and distress) that are routinely monitored and reported for quality improvement purposes, and will also report palliative care data annually to the National Palliative Care Registry™.

- **Skills Training**: Institution provides opportunities for training and clinical support to ensure all clinicians are confident in their ability to provide generalist/primary palliative care services that include goal-directed communication, as well as assessing and addressing pain, symptoms, and distress for patients, survivors, and families and/or make appropriate referrals for specialist palliative care team consultations.
Resources

Society resources:
1. Palliative care patient/family brochures
   - Society palliative care brochure
   - Society pediatric palliative care brochure
2. Patient/family palliative care information videos
   - ACS palliative care video
   - ACS pediatric palliative care video
3. PREPARE QOL decision-making online tool through partnership with www.prepareforyourcare.org
4. Health system information sheet (appendix)
5. Cancer.org palliative care content
6. National Cancer Information Center 24/7 phone assistance (1-800-227-2345)

In addition, CAPC offers a range of palliative care tools, training, and technical assistance resources available for every level of experience – whether an institution is just thinking about getting started in building a palliative care team, or already has a team fully integrated within their health system. CAPC supports websites for professionals and patients.

Society account managers can help identify specific CAPC resources tailored to support your institution’s particular needs. Here are links to a selection of CAPC’s topline offerings:

- National Palliative Care Registry™ and summary reports
- Frequent topical webinar offerings and an annual multi-day National Seminar (CAPC national seminar registration discount is available to Society partners)
- Hands-on training and mentoring through Palliative Care Leadership Centers
- Improving Palliative Care (IPAL) project for building outpatient palliative care programs
- “How-to” manual for building a successful hospital-based palliative care program

American Cancer Society 2014
Through its new “CAPC Campus” coming in January 2015, a variety of new CAPC online resources and CME/CEU offerings will be available. These will provide palliative care skills information and training relevant to all health systems and professionals.

Online curricula available beginning in 2015 will include:

- Pain Management
- Communication Skills
- Operational information

Details on the initial CAPC Campus offerings are provided on the next page. To support these initiatives, CAPC will become a membership organization beginning in 2015. Membership will be open to hospitals, health systems, hospices, and community healthcare organizations.

Please click this link for more information about CAPC membership and associated benefits.

Many hospitals have already committed to CAPC membership in its inaugural year. Some of these institutions secured financial support for membership through their third-party payers and/or philanthropic funding.

Please contact your Society account manager to learn more about how we can support your institution in its palliative care integration efforts. If you need assistance identifying your account manager, please contact Rebecca Kirch (Rkirch@cancer.org), the Society’s Director of Quality of Life and Survivorship.

Together we can save lives and prevent suffering
## CAPC Campus: 2015 Online Curriculum

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