

# Putting Quality of Life in Prime Time: Palliative Care Resource Guide



Together we can save lives and prevent suffering



This guide was developed by the American Cancer Society in consultation with the Center to Advance Palliative Care (CAPC) to support palliative care integration efforts.



## CONTENTS

Palliative Care: A Lifeline to Quality of Life	3
The New Paradigm in Health Care Delivery	4
What is palliative care?	4
Generalist plus specialist palliative care	4
Why palliative care is important to cancer patients and survivors	5
How palliative care works with psychosocial oncology care	6
How palliative care works with impairment-driven cancer rehabilitation	6
A rising trend in hospitals and health systems	7
Palliative Care: What's in a name?	8
Research provides solid evidentiary foundation	9
Quality improvement initiatives promoting palliative care integration	10
How palliative care is paid for	10
Advancing a quality of life public policy advocacy agenda	11
Pain policy and advocacy	12
Partnering to advance quality care objectives	13
Resources (adult and pediatric palliative care)	14

### 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. To improve quality of life at any age and any disease stage, the Society places a priority on supporting health system and practitioner efforts to integrate core palliative care principles into all facets of the health care delivery system.

Evidence has established the importance of pairing palliative care, including psychosocial support, with oncology treatment for adults and children in all care settings throughout cancer treatment and across the continuum of survivorship. Palliative care also is naturally aligned with other interventions such as cancer rehabilitation that focus on treating specific impairments and improving function as well as alleviating symptoms. Together, these [integrated services](#) offer essential support for maintaining patient and family quality of life during and after disease-directed treatment.

### QUALITY CARE ESSENTIAL ELEMENTS



Building on the work of palliative teams now in place at the majority of U.S. hospitals, integration in mainstream medicine of palliative care and other aspects of quality of life focused care is achievable and essential to improve the quality of care for all seriously ill adults and children. These links provide additional information about the value of palliative care integration to quality of life and the momentum building behind the movement to help patients and families survive and thrive:

- [JAMA Oncology 2015 Advancing a QOL Agenda in Cancer Advocacy](#)
- [Health Affairs blog 2015 Building a QOL National Movement](#)
- [NEJM 2013 Early Specialty Palliative Care — Translating Data in Oncology into Practice](#)

## 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 through the end of life. Palliative care services should be accessible in all adult and children's hospitals, cancer centers, and community care settings, including at home.

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 patients' needs, and helping patients and their families have a voice in realizing their life goals. This team-based care includes physicians, nurses, social workers, and others (such as psychosocial counselors, chaplains/spiritual counselors, rehabilitation clinicians, physician assistants, pharmacists, etc.).

Palliative care teams improve care 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

### Generalist plus specialist palliative care

While outpatient and community-based palliative care service models are emerging, hospital-based palliative care teams providing consultation services remain the most prevalent model of palliative care service delivery. These services usually involve specialty level palliative care for difficult-to-manage symptoms, complex family dynamics, and challenging care decisions regarding the use of life-sustaining treatments. But not all hospitals have palliative care teams. Moreover, the number of specialist-level palliative care practitioners available is not sufficient to manage all the palliative care needs of all seriously ill patients in all care settings.

Forward-thinking health systems now recognize the concurrent need for [specialist plus generalist palliative care](#) in delivering quality care and building sustainable programs. The approach promotes development of both generalist or primary palliative care (skills all clinicians should have, such as basic symptom management and communication supporting goal concordant care) and specialist palliative care (specialized skills for managing more complex and difficult cases) so they can coexist, support each other, and expand palliative care delivery.

System-wide implementation of [primary palliative care trigger criteria](#) for screening patients' needs can help support these integration efforts, together with initiatives to improve core “generalist” or “primary” palliative care communication, assessment, and treatment skills among all practitioners— including attending physicians, nursing staff, social workers, chaplains, and other frontline professionals involved with routine patient care.

CAPC offers courses, webinars, virtual office hours, topic-specific discussion forums and other resources that support institutional efforts to improve care quality by expanding palliative care delivery across the continuum in all care settings. These resources include online generalist plus specialist palliative care skills [training curricula](#) associated with CEUs, and a few free [course demos](#) are available. In addition, VitalTalk offers a selection of [advanced clinical communication skills resources](#) for oncology professionals that include talking maps, an i-phone app, live trainings and other tools for improving cancer program quality as specifically called for in recommendations of two recent Institute of Medicine reports, [Quality Cancer Care \(2013\)](#) and [Dying in America \(2014\)](#).

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

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, and aligning this with impairment-driven cancer rehabilitation services and psychosocial support, 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](#), “*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.

## How palliative care works with psychosocial oncology care

Psychosocial oncology care provides essential emotional support for people with cancer and should be available from trained behavioral health professionals across the care continuum for all adults, children and family members who need it. Psychosocial oncology professionals may be imbedded within the palliative care team, in the cancer center, or available by referral to community resources. Regardless of the care setting, screening for patient and family psychosocial distress as part of overall physical and emotional functional assessment is essential to providing quality cancer care and requires communication and coordination among the psychosocial, palliative, and oncology treatment teams.

A [Psychosocial Distress Screening Standard 3.2](#) from the Commission on Cancer has been designated for 2015 phase-in requiring accredited cancer centers to develop and implement a process so that all people with cancer are screened for psychosocial distress, receive resources and/or referrals for care to address the reasons for the distress, and receive routine follow-up to assess ongoing psychosocial needs. As cancer treatment centers implement methods to meet this standard, it is important to align and coordinate provision of psychosocial care with ongoing palliative care as well as oncology care and oncology rehabilitation as needed. The [ACS distress screening webinar](#) provides more detailed information about implementing the standard in practice.

The following links provide more detailed information about the CoC patient-centered care standards and resources available supporting their achievement:

- [Society's Collaborative Action Plan Guide on patient-centered standards](#)
- [Alliance for Psychosocial Oncology Care Resource Guide](#)

## How palliative care works with impairment-driven cancer rehabilitation

Physical and mental impairments may significantly reduce patients' and survivors' ability to function, resulting in disability and poor quality of life. There are hundreds of different impairments that may develop due to preexisting medical problems, the cancer itself, or cancer treatment. Examples of these include muscular weakness or paralysis, swallowing or speech problems, lymphedema, rotator cuff impingement, and physical disability as a result of major surgery. It is important to identify preexisting problems shortly after diagnosis and identify worsening or new issues all along the care continuum.

Although general exercise and behavioral interventions are important and contribute to the overall health and well-being of patients and survivors, they should not be confused with [impairment-driven cancer rehabilitation](#) that focuses on the diagnosis and treatment of specific cognitive and physical problems that are best addressed by qualified rehabilitation health care professionals such as physiatrists (doctors that specialize in

rehabilitation medicine) and physical, occupational, and speech therapists. It is very common for patients and survivors to have multiple impairments, and these should be treated with an interdisciplinary rehabilitation approach. The [ACS cancer rehabilitation webinar](#) provides detailed information about the importance of integrating these services to improve quality of cancer care.

Interdisciplinary healthcare professionals from oncology, palliative care, psychosocial care, and rehabilitation should work together to coordinate the medical services that will provide the best care possible supporting quality of life for all patients and survivors.

### **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 many hospitals now 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](#) 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. Subsequently, the [Measuring What Matters](#) consensus recommendation (published in 2015) provides hospice and palliative care program performance improvement measures through a collaborative effort of the American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nurses Association (HPNA).

The National Cancer Institute’s Community Cancer Centers Program has also produced a helpful [palliative care self-assessment matrix](#) tool tailored for cancer center use that aligns with key palliative care quality domains. This [ACS palliative care webinar](#) features practical information about using the matrix within your institution.

Palliative care is expected to increase as the public becomes more aware of its benefits. The Society and its advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN) are working with CAPC, AAHPM, HPNA, and other partners to help raise awareness about palliative care by giving people the words to use to get the care they need.

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

Using consistent and clear messages to explain palliative care really matters. A [consumer research study](#) commissioned by CAPC, the Society, and ACS CAN in 2011 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 want 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 keeps 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.

Because improved communication and messaging 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 resources:

- [ASCO palliative care resources](#)
- [NCCN Palliative Care Guidelines update bulletin](#)
- ACS [adult](#) and [pediatric](#) palliative care brochures
- CAPC [YOU are a bridge video](#)
- CAPC [adult](#) and [pediatric](#) online consumer palliative care information



## Research provides solid evidentiary foundation

Studies have demonstrated that palliative care is associated with better quality of life and mood, improved symptom control, more appropriate health resource use, increased patient and caregiver satisfaction, health care savings, and possibly even survival. This research has helped drive the momentum behind greater integration of palliative care and oncologic care in both inpatient and ambulatory care settings.

- **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 N Engl J Med. 2010)
- A [2013 qualitative study](#) published in follow up described salient elements of the 2010 study's early palliative care clinic visits, which emphasized managing symptoms, strengthening coping, and cultivating illness understanding and prognostic awareness. During critical clinical time points, palliative care and oncologic care visits had distinct features that suggested a key role for palliative care involvement and enabled oncologists to focus on cancer treatment and managing medical complications. (Yoong JAMA Intern. Med. 2013)

- **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 was associated with reductions of \$1700 per admission for live discharges and reductions of \$4900 per admission for patients who died in the hospital. This translated 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 research. Click on this link to find information about [how to apply for Society research grant](#). ACS grant application deadlines are October 15 and April 1.

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](#).”

### Quality improvement initiatives promoting palliative care integration

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:

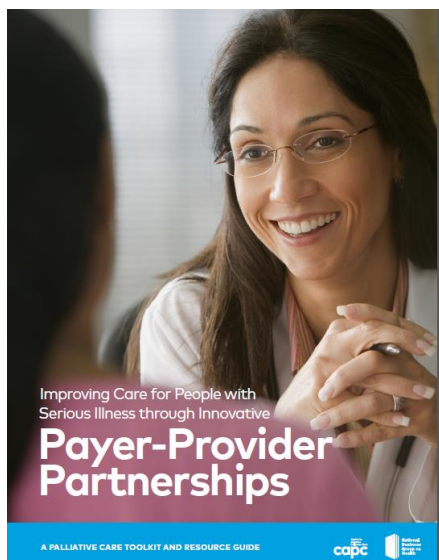
- **American Society of Clinical Oncology** (ASCO) [provisional clinical opinion](#) for integrating palliative care with oncology in all patients presenting with high symptom burden and/or metastatic cancer
- **The Commission on Cancer** [patient centered care standards](#) include a clinical requirement (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 palliative care is 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 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 on page 9.

CAPC has produced a helpful [palliative care payer provider 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.



The toolkit presents 4 categories of content:

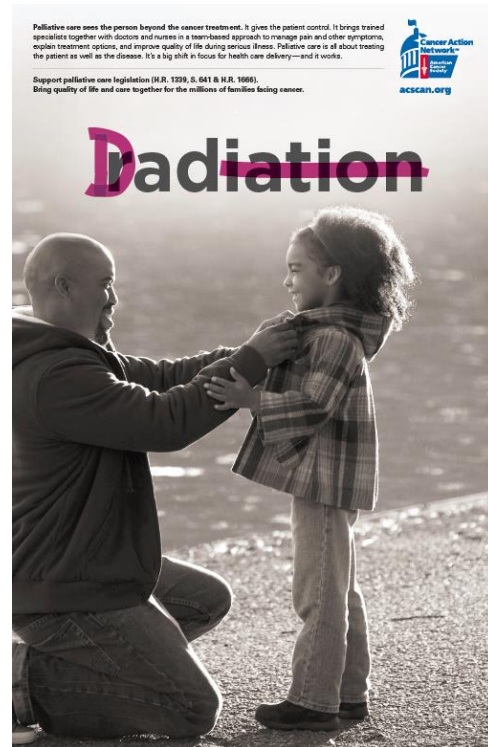
- **What is palliative care and why it's important:** Information about the types of palliative care and the essential clinical and structural characteristics that make it effective
- **Payer strategies and case studies:** Opportunities payers have for integrating palliative care into their programs and products, and what other payers are doing
- **Getting started:** First steps to developing a palliative care strategy
- **Tools and resources:** A set of tools and resources for payers, employers, and providers, including palliative care quality standards and best practices, and useful checklists

### **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 formation of a [Patient QOL Coalition](#) which convenes multiple national organization members focused on promoting palliative care and other quality of life care-focused 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 content evaluating states' palliative care (p. 38) and pain (p. 41) public policy landscape in its quality of life section, offering a handy reference tool advocates in state comprehensive cancer plan coalitions and other alliances can use to coordinate action.

## Ads from ACS CAN QOL Campaign



### Pain Policy and Advocacy

ACS CAN also advocates for [balanced pain policies](#) in partnership with the American Academy of Pain Management's State Pain Policy Advocacy Network ([SPPAN](#)) and other collaborators. 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.](#)

This [research report](#) and [webinar](#) features quantitative and qualitative findings of a 2015 collaborative study revealing disconnects in pain-related communications between prescribers (including oncologists) and patients. This earlier article details opportunities for [advancing cancer pain control as a health care priority.](#)

Comprehensive information about specific federal and state policies associated with pain care and the principle of improved balance are available at [Pain and Policy Studies Group.](#)

An interactive web community for pain research is available for investigators in academia, industry, medicine, and other fields through [The Pain Research Forum.](#) For clinical care, CAPC offers [online pain management curricula](#) with CME/CEU credits available for social work, nursing, and medicine.

## Partnering to advance quality care objectives

As hospital uptake continues to rise, bringing palliative care services into the community for all seriously ill adults and [children](#) is essential to spread its reach. Society **staff partners** *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. They also 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 and shared-decision making that ensures treatment decisions and care transitions across the continuum align with individual patient and family values.
- **Quality Improvement:** Institutions designate 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. Palliative care teams will also report data annually to the [National Palliative Care Registry](#)<sup>™</sup>.
- **Skills Training:** Institutions provide 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 PALLIATIVE CARE MATERIALS

### Patient/family information

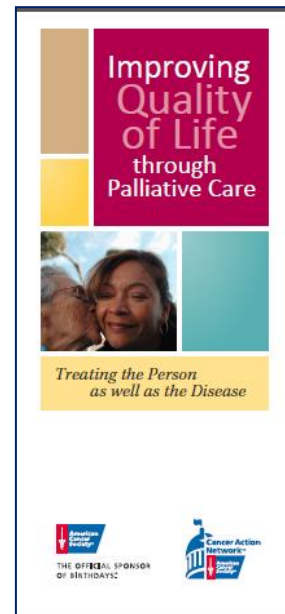
- [Society palliative care brochure](#)
- [ACS palliative care video](#)

### Pediatric palliative care:

- [Society pediatric palliative care brochure](#)
- [ACS pediatric palliative care video](#)

[ACS cancer.org palliative care content](#)

ACS National Cancer Information Center 24/7 phone assistance (1-800-227-2345)



## Resources from collaborative partners

### Communication tools: QOL and palliative care



**For Patients:** QOL decision-making online tool for patients and families developed with support from ACS: <https://www.prepareforyourcare.org/>



**For Practitioners:** Talking maps and other tools developed through partnership with ACS: <http://vitaltalk.org/quick-guides>



**For Parents:** “A Parent’s Guide to Enhancing Quality of Life in Children with Cancer” pediatric palliative care handbook developed through partnership with ACS: <http://www.acco.org/we-can-help-for-kids/books/>



**For Everyone:** A QOL conversation game for living and dying well to help transform the experience of care planning for staff, patients, families, and communities: <http://mygiftofgrace.com/>

## Generalist and specialist palliative care resources



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 both [professionals](#) and [patients](#).

Society health system partners can help identify specific CAPC resources tailored to support your institution's particular needs. Here are links to CAPC's topline offerings:

- [National Palliative Care Registry™](#) and [summary reports](#)
- Annual multi-day [National Seminar](#) (*registration discount available to ACS partners*)
- Hands-on training and mentoring through [Palliative Care Leadership Centers](#)
- Frequent topical [webinar and virtual office hours](#) (*requires CAPC membership login*)
- Improving Palliative Care (IPAL) project for [outpatient palliative care programs](#)
- “How-to” manual for [building a successful hospital-based palliative care program](#)

## Additional pediatric palliative care resources:

- Online support community and resources for parents of seriously ill children:
  - [Courageous Parents Network](#)
- Pediatric palliative care awareness and communication:
  - [What is pediatric palliative care](#)
  - [Conversations Matter campaign](#)
  - [Pediatric Starter Kit: Having the Conversation with Your Seriously Ill Child](#)
- Children's oncology camps community locator tools:
  - [KOA Care Camps interactive map](#)
  - [Children's Oncology Camping Association International member map](#)

## CAPC membership information

[CAPC membership](#) is open to hospitals, health systems, hospices, and community healthcare organizations, and provides unlimited access to all CAPC resources that support palliative care delivery and quality across the continuum. One membership fee covers the cost of training, tools, hands-on technical assistance, and expert resources for the entire staff of each member institution. Many hospitals are already CAPC members, and some of these institutions secured financial support for their membership through their third-party payers and/or philanthropic funding.

Through its new “**CAPC Campus**,” a variety of new [CAPC online resources](#) associated with CME/CEU credits are available for member organizations. These curricula provide palliative care skills information and training material relevant to all health systems and all health professionals. Click this link to view [course demos](#). Online curricula currently available for members include:

- Pain Management
- Communication Skills
- Operational information

Please contact your Society staff partner to learn more about how we can support your institution in its palliative care integration efforts. If you need assistance identifying your Society staff partner, please contact Rebecca Kirch ([Rkirch@cancer.org](mailto:Rkirch@cancer.org)), the Society’s Director of Quality of Life and Palliative Care.

*Together we can save lives and prevent suffering*

