

California Health Care Foundation

HEALTH CARE THAT WORKS FOR ALL CALIFORNIANS





A Resource Guide for Public Hospital Champions and Specialists

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Introduction

<u>Rationale</u>: To provide the highest quality of care for all patients with serious illness, access to palliative care is imperative. But to meet the needs of this growing patient population, the palliative care model must shift from a specialist-driven model to one that supports the availability of both primary (or generalist) palliative care and specialty palliative care. Primary palliative care (basic palliative care skills all clinicians should have) is provided to patients by their primary care provider and other medical specialists. Specialty palliative care (skills for managing more complex and difficult cases) is provided by specialists for patients who need it.¹

Integrating palliative care best practices and principles into the routine care of all patients with serious illness, requires skill building in the core domains of palliative care for all clinicians who care for patients with serious illness. It also requires quality improvement efforts that integrate palliative care processes into routine care across various specialties, care settings, and service lines. Palliative care specialists and champions are optimally positioned to lead efforts in both areas.

<u>Audience and Purpose</u>: This guide was developed for palliative care champions and specialists who work in California Public Hospitals, to assist them in developing quality improvement projects to integrate palliative care into routine care across a range of service lines and patient populations. Palliative care champions and specialists from 10 of California's public hospitals, along with an expert panel, developed the guide. The guide includes:

- Palliative care and advance care planning/serious illness communication resources.
- **Resources** for frontline clinicians, patients, and families, that palliative care champions and specialists can use as part of palliative care education and improvement efforts.
- Free resources, as well as those available for a fee or with a membership.
- Train-the-trainer programs and implementation resources for systems that palliative care specialists and champions can use to support their program planning and development.

¹ Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. N Engl J Med. 2013 Mar 28;368(13):1173-5. doi: 10.1056/NEJMp1215620.

Definitions:

Serious Illness: a health condition that carries a high risk of mortality AND either negatively impacts a person's daily function or quality of life, OR excessively strains their caregivers.²

Palliative care: focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care. Palliative care attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness. Through early integration into the care plan for the seriously ill, palliative care improves quality of life for the patient and the family.³

Primary or generalist palliative care: palliative care that is delivered by health care professionals who are not palliative care specialists. These include primary care clinicians; physicians who are disease-oriented specialists (e.g., oncologists and cardiologists); and, nurses, social workers, pharmacists, chaplains, and others who care for the seriously ill but are not certified in palliative care. ¹

Palliative care specialists: clinicians who have specialized training and certification in palliative care and provide consultative services.

Frontline clinicians: clinicians who have primary responsibility for the care of patients, e.g. bedside nurses, primary care physicians, hospitalists, surgeons, social workers, chaplains, as well as specialists in fields with prevalent serious illness, such as cardiology, oncology, critical care, nephrology, etc.

Palliative care champions: clinicians who primarily work within a service line other than palliative care, who advocate for palliative care and support their colleagues to integrate palliative care into their area of practice.

² Kelley AS, Bollens-Lund E. Identifying the Population with Serious Illness: The "Denominator" Challenge. J Palliat Med. 2018 Mar;21(S2):S7-S16.

³ National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. https://www.nationalcoalitionhpc.org/ncp.

Palliative Care Resources

The following resources, grouped by organization, address a number of domains of palliative care. e.g. pain and symptom management, psychosocial and spiritual care, advance care planning, serious illness communication.

These resources are relevant to a range of patient populations.

Organization Description	Free Resources	Paid or Membership Resources	Train the Trainer and Resources for Systems
Center to Advance Palliative Care (CAPC) A national organization dedicated to increasing the availability of quality health care for people living with a serious illness.	Get Palliative Care is a comprehensive website with a wealth of free resources for patients and families. Includes information about palliative care domains, a provider directory, and support and educational resources. Membership required to access most clinician resources. Some courses are available to non-members, e.g. <u>An In-Depth Look At</u> <u>Palliative Care And Its Services</u>	Comprehensive on-line palliative care curriculum for all clinical disciplines, with continuing education credits. Courses are free for clinicians at member organizations. Membership is \$3500/year for safety net hospitals.	Membership includes a broad range of <u>tools for building and</u> <u>strengthening palliative care</u> <u>programs</u> , including tools for demonstrating value and assessing quality, as well as content for the <u>ICU</u> , <u>ED</u> , and <u>pediatrics</u> .
California State University – Shiley CSU Institute for Palliative Care The Institute offers high-quality palliative care introductory and continuing education courses for a wide range of health professionals.	<u>Community resources & free</u> <u>caregiver handbook</u> <u>Blog</u>	Online courses, instructor-led and self-paced, for a range of clinical disciplines. Continuing education credits offered. Cost varies by course, approximately \$130 per credit hour.	Organizational training offered, including team training and starting a community-based palliative care program.

Palliative Care Resources - Continued

Organization Description	Free Resources	Paid or Membership Resources	Train the Trainer and Resources for Systems
End-of-Life Nursing Education Consortium (ELNEC) Comprehensive undergraduate, graduate, and continuing education for nurses in palliative care, including pain and symptom management, communication, psychosocial issues, and spiritual care.	N/A	Online courses: \$59.95 per curriculum or \$19.95 per module. Institutional pricing available. In person 2-day trainings, nationally and regionally. Tailored courses for critical care, oncology, geriatrics, pediatrics, advanced practice.	ELNEC is a train-the-trainer program. Upon program completion, <u>free materials</u> are available for teaching.
Education for Physicians in End- of-life Care (EPEC) Education for healthcare professionals from a range of disciplines in the essential clinical competencies of palliative and end-of-life care.	N/A	Distance learning includes 16 modules that consist of information, video cases, and discussion boards. AMA PRA Category 1 Credit(s)™ per module, \$30 per module. Tailored curricula for emergency medicine, pediatrics, veterans, caregivers.	Become an EPEC Trainer Conference: 2-day conference to learn to teach the essential clinical competencies of palliative care to others. Includes clinical content and teaching methodology. Participants receive EPEC educational materials including Curriculum, slides, and videos. Cost: \$1295.
Palliative Care Network ofWisconsin - Fast Facts andConceptsConcise, practical, peer-reviewed, and evidence-basedsummaries on a range ofpalliative care topics.	<u>Website</u> <u>Mobile Application</u>	Fast Facts CME Online CME. \$52.50 covers 8 courses, on a range of topics.	N/A

Palliative Care Resources - Continued

Organization Description	Free Resources	Paid or Membership Resources	Train the Trainer and Resources for Systems
Harvard Medical School Center for Palliative Care Offers in-person continuing education courses, and an interprofessional fellowship.	N/A	Practical Aspects of Palliative Care (PAPC): 3-day introduction to palliative care clinical practice for physicians, nurses, social workers, and other clinicians.	Palliative Care Education and Practice (PCEP): 2-week course for physicians, nurses, and social workers. In depth coverage of clinical topics, mentorship in a leadership project. Adult and pediatric tracks.
Stanford University - Palliative Care Training Portal and Palliative Care Always Free on-line courses in palliative care.	Stanford Palliative Care <u>Training Portal</u> : learning modules, resources and training materials on a range of topics (e.g., dyspnea prognostication, bereavement, opioid conversion). <u>Palliative Care Always</u> : longitudinal 5-month online, case-based course designed for health care practitioners who work in cancer care.	N/A	N/A

Advance Care Planning and Serious Communication Resources

Organization Description	Free Resources	Paid or Membership Resources	Train the Trainer and Resources for Systems
Ariadne Labs Serious Illness Care Program The program's goal is for every seriously ill patient to have more, better, and earlier conversations with their clinicians about their goals, values, and priorities that will inform their future care.	At the center of the program is the <u>Serious Illness</u> <u>Conversation Guide</u> , which offers clinicians language to ask patients about their goals, values, and wishes. Free registration provides access to a <u>community of</u> <u>practice</u> with implementation support including peer mentoring, downloadable materials, videos, webinars.	 The Serious Illness Conversation Guide is one element of a multi- component program creating system-level support for clinicians to have these important conversations with their patients. For a fee, institutions can join a <u>collaborative</u> that provides health systems with the roadmap, tools, and support to implement the Serious Illness Care Program. This support includes a) communication skills training to teach others to use the Serious Illness Conversation Guide, and b) implementation strategies to identify patients, prompt clinicians, document discussions, and monitor progress. Financial assistance is available: inquire at sicollaborative2019@ariadnelabs.org. 	
Coalition for Compassionate Care of California (CCCC) Interdisciplinary partnership of leaders from health care systems and organizations, government agencies, consumer organizations, and the public. Advocacy, education, and resources to expand palliative care.	A number of free resources are available, including: <u>Advance care planning tools</u> <u>and resources</u> : discussion guides, decision aids, information about advance directive and POLST forms for clinicians and patients/families, and billing information. <u>End of Life Option Act</u> : information for patients and families.	Annual palliative care summit Webinars on a range of palliative care topics: some are free, some cost up to \$99. Discount for members.	Trainings offered on promoting advance care planning, culturally congruent care, end of life options act, POLST.

The following organizations provide leading advance care planning and serious illness communication resources.

Advance Care Planning and Serious Communication Resources - Continued

Organization Description	Free Resources	Paid or Membership Resources	Train the Trainer and Resources for Systems
VitalTalk Non-profit organization that offers resources and training on advanced serious illness communication skills. Appropriate for clinicians from a range of specialties and disciplines.	Mobile Application <u>Videos & quick guides</u> including: delivering serious news, advance care planning, discussing prognosis, and goals of care. Videos can be <u>downloaded</u> for teaching purposes. <u>Blog</u>	Online course Delivering Serious News \$110 / 5 CME credits. In person introductory <u>Mastering Tough</u> <u>Conversations workshops</u> , 4 per year in Bay Area and AAHPM/HPNA pre-course each year. \$500 / 7 CME credits.	<u>Faculty development course:</u> 4-day course to learn to teach serious illness communication workshops. \$5000. <u>Institutional courses:</u> VitalTalk can lead a workshop for your system.
PREPARE for Your Care Online evidence-based resource that helps people learn about and prepare for medical decision making. Uses video stories in English and Spanish.	Web based advance care planning tool: guides users in exploring wishes, discussing them with family, friends, and medical providers, and documenting them. Easy-to-Read Advance Directives: legally-binding directives available for all 50 states in English and Spanish.	Most PREPARE resources are free and can be used without a license. PREPARE can be <u>licensed</u> by healthcare and other organizations. A license with the Regents of the University of California is required if PREPARE is to be used in research, quality improvement, or clinical demonstration projects.	
Advance Care Planning (ACP) Decisions Non-profit organization that offers evidence-based, expert- reviewed video decision support tools for patients and families.	<u>Free Patient Content</u> : some videos about advance care planning, POLST, and palliative care.	ACP Decisions partners with hea enhance advance care planning tools. Organizations can tailor th Decisions video library, which co including decision aids, education patients, and caregivers, and tra- videos. Content available in 20 l	using video decision aids and neir own ACP strategy using ACP onsists of over 280 videos, onal videos for clinicians, aining and implementation

Additional Free Resources - Continued

Blogs

- <u>GeriPal</u> (Geriatrics and Palliative care): forum for discourse, recent news and research, and free-thinking commentary. Ongoing podcast features interviews with national leaders on a range of topics.
- Pallimed: hospice and palliative care research, news, opinion, and media coverage of hospice and palliative care issues.

Guides and Guidelines

- Weaving Palliative Care into Primary Care: A Guide for Community Health Centers (California Health Care Foundation): introduction to primary palliative care and a detailed description of the steps required to plan, build, and integrate a primary palliative care program into a clinic setting. Provides planning tools and worksheets to help community health centers get started. Multiple appendices include primary palliative care resources from a wide variety of organizations and experts.
- Clinical Practice Guidelines for Quality Palliative Care, 4th edition (National Consensus Project): defines gold-standard palliative care for all people living with serious illness, regardless of their diagnosis, prognosis, age or setting. This edition has specific content on generalist palliative care, and includes practice examples to guide improvement. Endorsed by more than 80 organizations nationally.

Emergency Department

Palliative Care Screening Tool in the Emergency Department. Reference: George N, Barrett N, McPeake L, Goett R, Anderson K, Baird J. Content Validation of a Novel Screening Tool to Identify Emergency Department Patients With Significant Palliative Care Needs. Acad Emerg Med. 2015;22:823-37.

Homelessness

- National Health Care for the Homeless Council, End of Life Care Resource Page: includes recommendations for caring for people experiencing homelessness—includes advance care planning and case studies.
- Homeless Palliative Care Toolkit: A research informed toolkit with information and resources for frontline staff supporting people who are homeless and who have significant health needs. Includes focus on identifying clients in need of palliative care at the time staff have a concern about a client's deteriorating health, and provides resources, tools and activity worksheets to help in planning and providing person centered, multiagency care for homeless people. Developed by a partnership between a palliative care group and a homeless charity organization in the United Kingdom.

Advance Care Planning and Serious Communication Resources - Continued

Interpreters

Interpreting in Palliative Care Curriculum (California Health Care Foundation): free, downloadable seven-hour workshop curriculum designed for health care interpreter trainers to use in preparing experienced medical interpreters to work in palliative care settings. Curriculum is also available as a self-paced web-based course for \$35 through the Health Care Interpreter Network (HCIN).

Nurses' Roles in Serious Illness Communication and Palliative Care

- IMPACT-ICU (Integrating Multidisciplinary Care into the ICU) integrates palliative care into critical care by training and supporting bedside nurses, especially around serious illness communication. Tools include:
 - Webinars through the American Association of Critical-Care Nurses (AACN): <u>Palliative Care in the ICU: Critical</u> <u>Communication Skills</u>, <u>Palliative Care in the ICU: A 360° View of The Nurse's Role</u>, <u>Palliative Care in the ICU:</u> <u>Communication Skills in Practice</u>. Viewing is free (need to create an AACN log-in). AACN members receive free CEUs. CEUs are \$10 for non-members.
 - <u>Videos and downloadable content</u>: can be used to guide presentations. Includes a pocket card, study guides, and goals/skills sheets. Videos can be streamed from <u>VitalTalk</u> or downloaded from <u>Vimeo</u> for use off-line.
 - <u>In person workshop</u>, for faculty who have been trained in small group role-play facilitation. We recommend a <u>VitalTalk</u>
 <u>Faculty Development</u> course or the equivalent. Consultation with the IMPACT-ICU team can be requested <u>here</u>.

Oncology

- Clinical Practice Guidelines for Supportive Care: Palliative Care (National Comprehensive Cancer Network): evidence-based, consensus-driven recommendations made by the NCCN Guidelines panels. Includes guidelines, as well as information about services that should be provided as a basic standard of care, as well as additional services that provide major improvements in disease outcomes when they can be implemented. Note: must register to access resources.
- Palliative Care Resource Page (American Society of Clinical Oncology): includes information about meetings & courses, guidelines, tools and resources, and advocacy and policy statements; patient resources; and a journal collection.

Prognostication in Older Adults

<u>ePrognosis</u>: repository of published geriatric prognostic indices where clinicians can go to obtain evidence-based information on patients' prognosis. Easy to use on-line calculators to estimate prognosis, as well as information about applying prognosis to cancer screening and prognostic communication.

Advance Care Planning and Serious Communication Resources - Continued

Pediatrics

- <u>American Academy of Pediatrics Section on Hospice and Palliative Medicine</u>: includes information about palliative care for children aimed at both professionals as well as families, including policies, resources, curricula, and newsletters.
- <u>Children's Project on Palliative/Hospice Services: ChiPPS</u>: ChiPPS serves as the National Hospice and Palliative Care Organization's (NHPCO) pediatric advisory council. Their website includes information about palliative care and hospice for children, as well as professional resources and education, and information for families.

Surgery and Trauma

- American College of Surgeons Trauma Quality Improvement Program Palliative Care Best Practices Guidelines: recommendations for identifying and addressing palliative care needs in injured patients and their families. Includes clinical content and performance improvement guidance.
- Best Case / Worst Case: communication framework for face-to-face discussions about treatment options in the context of serious illness. Designed to help physicians discuss options with frail older patients and their families to achieve treatment decisions that align with patient preferences.