



# Appropriate Use of Medical Resources

Aligning Treatment with Patient  
Priorities in the Context of Progressive  
Disease for Use of the ICU

Developed with resources from:



National Hospice and Palliative Care  
Organization



# Aligning Treatment with Patient Priorities in the Context of Progressive Disease for Use of the ICU

To access the toolkit, visit [www.aha.org/appropriateuse](http://www.aha.org/appropriateuse).

Developed with resources from:

Center to Advance Palliative Care (CAPC)

Coalition to Transform Advanced Care (C-TAC)

Education in Palliative and End-of-life Care (EPEC®)

National Hospice and Palliative Care Organization (NHPCO)

Society of Critical Care Medicine (SCCM)

The health care system should encourage early intervention and discussion about priorities for medical care in the context of progressive disease and robust communication between patients and their providers to understand the patient's goals. These discussions should address the likelihood of acceptable (to the patient) recovery, the risk of long-term impairment or death, the options for palliative care co-management at the same time as disease-directed treatment and the benefits of hospice care in the framework of the patient's priorities.

## User Guide

The toolkit is composed of three sections:

**Hospital and Health System Resources** – This section includes assessment guides, PowerPoint presentations, key statistics and findings, position statements and resources supporting the appropriate use of the ICU for imminently terminal illness.

**Clinician Resources** – This section includes fact sheets, a palliative care screen, tip sheets, communication guides, articles, a webcast and recommendations regarding end-of-life care in the ICU.

**Patient Resources** – In addition to two overview pieces, this section includes resources regarding palliative care, advance care directives, and ICU/treatment-specific concerns for patients, their families and caregivers.

## Hospital and Health System Resources

### *Implementing Decision Making Resources for Serious Illness*

Developed on behalf of C-TAC, this slide presentation shares an overview of the issues surrounding advanced illness care in the United States including demographic and utilization trends, cultural issues and models that work. To download, go to [bit.ly/1h9xDvW](http://bit.ly/1h9xDvW).

### *Consumer Perceptions and Needs Regarding Advanced Illness Care: Are We Listening?*

This C-TAC consumer perceptions paper explores the communications gap between patients and family members and the health care providers they rely on when they are sickest and most vulnerable. The paper addresses confusion on advanced illness terminology, cost concerns, and how to improve communications regarding end-of-life care. To download, go to [bit.ly/1T17Sgh](http://bit.ly/1T17Sgh).

### *Continuum of Care Assessment*

Developed by NHPCO, this assessment guides an organization through determining strengths and gaps of services in providing a seamless continuum of care for patients with life-limiting illness. Steps in NHPCO's process include internal, competitor, community service, and organizational strength assessments, as well as prioritizing and mapping gaps and strengths, compiling community data and trends, determining return on investment, and implementation. To download, go to [bit.ly/1FZNWmY](http://bit.ly/1FZNWmY).

### *Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End-of-life*

"For over a decade, *Dartmouth Atlas* analyses have shown that care for a relatively homogenous population (chronically ill patients near the end-of-life) varies significantly across regions and hospitals. This report shows rapid improvement in many places, although patients in some hospitals continue to receive more aggressive and less palliative care than others." To download, go to [bit.ly/1FBTDnN](http://bit.ly/1FBTDnN).

### *Position Statement on Access to Palliative Care in Critical Care Settings*

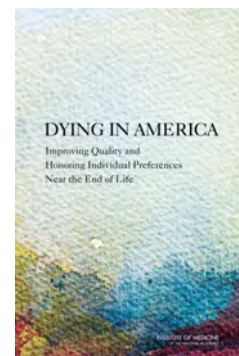
NHPCO issued this call to action “for professionals in critical care settings, palliative providers and hospital administrators to ensure the provision of palliative care....Access to palliative care for all patients in the critical care setting requires collaboration among health care professionals, changes in education processes, utilization of evidence-based practice, application of ethical principles and improvements in health care systems. Through this comprehensive, collaborative approach an environment that ensures the right of all patients in critical care settings and their family members to palliative care is achieved.” To download, go to [bit.ly/1ODWu5S](http://bit.ly/1ODWu5S).

### *NHPCO Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients*

Published in *Journal of Pain and Symptom Management*, this position statement recommends implementation of a written institutional policy addressing palliative sedation. The article provides definitions, addresses indications and recommended processes, continuation of concurrent life-sustaining therapies, artificial nutrition and hydration, education and clinical support, discusses frequency of use, and case and utilization review. To download, go to [bit.ly/1Qwlueg](http://bit.ly/1Qwlueg).

### *Dying in America: Improving Quality and Honoring Individual Preferences near the End-of-Life*

This consensus report from the Institute of Medicine finds that “improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end-of-life, but may also contribute to a more sustainable care system.” To download, go to [bit.ly/1KR0f9x](http://bit.ly/1KR0f9x).



## **Clinical Resources**

### *IPAL-ICU Improving Palliative Care in the ICU*

In an effort to integrate palliative care and intensive care across disciplines, CAPC, with support from the National Institutes of Health created IPAL-ICU, a central venue for sharing expertise, evidence and tools, along with links to colleagues, organizations and informational materials. Resources include CME/CEU courses, webinars and office hours, discussion forums, videos and podcasts and more. To access, go to [bit.ly/1H6pFIY](http://bit.ly/1H6pFIY).

### *Evidence-Based Palliative Care in the Intensive Care Unit: A Systematic Review of Interventions*

Published in *Journal of Palliative Medicine*, this systematic review concludes “existing evidence suggests proactive palliative care in the ICU, using either consultative or integrative palliative care interventions, decrease hospital and ICU [length of stay], do not affect satisfaction, and either decrease or do not affect mortality.” To download, go to [bit.ly/1PJYcTU](http://bit.ly/1PJYcTU).

### *Critical Care Delivery in the Intensive Care Unit: Defining Clinical Roles and the Best Practice Model*

Appearing in *Critical Care Medicine*, this article examines demographics and patterns of care in ICUs citing a SCCM study, Pediatric ICU Survey Data, and the work of the Committee on Manpower for the Pulmonary and Critical Care Societies. Also addressed is the need for multidisciplinary critical care, including intensivist, nursing, pharmacy, and respiratory therapy components. An assessment of the literature is provided, including practitioner-specific studies. To download, go to [bit.ly/1cQFXYy](http://bit.ly/1cQFXYy).

### *Recommendations for End-Of-Life Care in the Intensive Care Unit: A Consensus Statement by the American College of Critical Care Medicine*

In this article, recommendations to improve care in the ICU at the end-of-life include patient and family-centered decision making, ethical principles and practical aspects relating to the withdrawal of life-sustaining treatment, and symptom management. To download, go to [bit.ly/1JOFQjN](http://bit.ly/1JOFQjN).

## Fast Facts

Published in the *Journal of Palliative Medicine*, Fast Facts are “teaching tools that can be used for bedside rounds, as well as self-study material for health care trainees and clinicians.” Just four of the nearly 300 Fast Facts:

- Palliative Care and ICU Care: Pre-Admission Assessment
- Palliative Care and ICU Care: Daily ICU Care Plan Checklist
- The Family Meeting: End-of-life Goal Setting and Future Planning
- Palliative Care Consultation in the ICU

## Estimates of the Need for Palliative Care Consultation across United States Intensive Care Units Using a Trigger-based Model

This *American Journal of Respiratory and Critical Care Medicine* article discusses the impact of a trigger tool in the ICU to improve the timing and appropriate referral to palliative care consultation. To download, go to [bit.ly/1FyqDOE](http://bit.ly/1FyqDOE).

## Five Things Physicians and Patients Should Question

This Choosing Wisely list, identifying practices commonly used within critical care whose necessity should be questioned and discussed, was prepared as an initiative of the Critical Care Societies Collaborative, which includes the American Association of Critical-Care Nurses, the American College of Chest Physicians, the American Thoracic Society and the Society of Critical Care Medicine. To download, go to [bit.ly/1ORjjjg](http://bit.ly/1ORjjjg).

## Evaluation of Screening Criteria for Palliative Care Consultation in the MICU: A Multihospital Analysis

Using a palliative care screening tool, “medical intensive care unit (MICU) nurses at four hospitals screened patients upon admission during a 16-week period.” To download, go to [bit.ly/1KL2Ctx](http://bit.ly/1KL2Ctx).

## Palliative Care Screen Used in Study

Seven-item screen used for the study, implemented across the four MICUs. To download, go to [bit.ly/1IObizY](http://bit.ly/1IObizY).

## Clinical and Cost Outcomes for Triggered PC Consults in ICU: A Multi-Hospital Study

This poster, presented at the 2014 CAPC National Seminar, examines the validity and impact of the Palliative Care Screen found above. To download, go to [bit.ly/1S298y8](http://bit.ly/1S298y8).

## Clinical and Cost Impact of Early Palliative Care Screening and Consultation in the ICU

This abstract, from the 8th World Research Congress of the European Association for Palliative Care, shows that to make a difference in the use of resources, palliative care consults need to be started within the first four days of hospitalization. To download, go to [bit.ly/1KcFIQF](http://bit.ly/1KcFIQF).

## Education in Palliative and End-of-life Care (EPEC®)

The EPEC® curriculum combines didactic sessions, video presentations, interactive discussions, and practice exercises teaching fundamental palliative care skills in communication, ethical decision making, psychosocial considerations, and symptom management. Medical specialty curricula include oncology, emergency medicine, long-term care, for Veterans and (currently in production), pediatrics. To access, go to [bit.ly/1NrYWOH](http://bit.ly/1NrYWOH).

## CASE EXAMPLES

### BAYLOR HEALTH CARE SYSTEM SUPPORTIVE AND PALLIATIVE CARE (SPC) SERVICES

#### AHA Circle of Life 2014 Award Winner

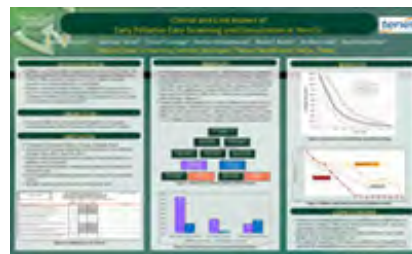
Baylor’s SPC program grew out of a clinical ethics program providing about 120 collaborative clinical ethics consultations yearly, most at the very end of life. The ethics consultation team could help negotiate a care plan, but could not treat pain or other suffering. Recognizing the need to reach seriously ill patients earlier, the Palliative Care program was launched in 2004.

Since the program began many innovations have been implemented including a comfort feeding program and utilization of volunteer doulas to accompany and comfort the seriously ill and dying. SPC extends to Baylor House Call program, providing comfort care and symptom management resources to the nearly 1,200 homebound elders the program serves.

Synergism with the critical care and emergency department led to development of “trigger tools” to systematically identify their SPC-appropriate patients. The results: more palliative care consults on admission from the ED, more direct hospice admits from the ED, and shorter ICU lengths of stay.

### A FORBIDDEN CONVERSATION

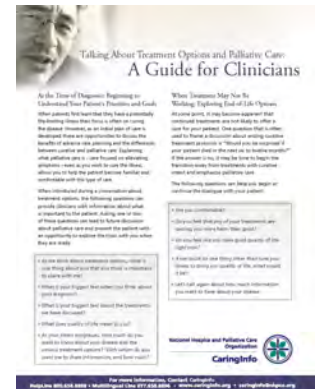
Published in SCCM’s *Critical Connections*, this ethics case study examines the balance between patient and physician autonomy. The case, in which discussion about death, dying and end-of-life care was forbidden by the patient’s and family’s religion, sheds lights on standards of decision making, autonomy and futility while honoring the values of all involved – the patient, family and clinicians.



## Communication Resources

### *Talking About Treatment Options and Palliative Care: A Guide for Clinicians*

NHPCO's guide provides clinicians with questions they can ask their patients at the time of diagnosis, in order to better understand the patient's priorities and goals, as well as explore end-of-life options. The guide also provides new approaches to communicating options as well as what a patient may be thinking when asking questions such as "what are my chances?" and "what would you do if you were me?" To download, go to [bit.ly/1fLT7yh](http://bit.ly/1fLT7yh).



### *Advice for Physicians Caring for Dying Patients*

Developed by NHPCO, this advice helps physicians discuss end-of-life treatment with their patients. Recommendations include placing advance directives, living wills and power-of-attorney documents in the patient's chart, as well as utilizing hospice and palliative care team members, chaplains, and social workers. To download, go to [bit.ly/1QwJqzI](http://bit.ly/1QwJqzI).

### *Improving End-of-Life Care through Better Clinician-Patient Communications*

In this inaugural webcast of SCCM's Project Dispatch, presenter J. Randall Curtis, MD, MPH, discusses his PCORI-funded study focusing on ensuring patients receive the care they desire through improved patient-clinician communication. To view, go to [bit.ly/1H8PLjR](http://bit.ly/1H8PLjR).

## Articles

### *The Impact of Advance Care Planning on End-of-Life Care in Elderly Patients: Randomised Controlled Trial*

The authors of this *BMJ* article show that for a university hospital in Australia, "advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives." To download, go to [bit.ly/1hSeyze](http://bit.ly/1hSeyze).

### *The Changing Role of Palliative Care in the ICU*

This *Critical Care Medicine Journal* article provides a definitive review on the topic of palliative care for ICU patients. With more than 150 references, it concisely summarizes the existing research on palliative care in the ICU and provides resources for clinicians and policy makers. To download, go to [bit.ly/1Xd6CSx](http://bit.ly/1Xd6CSx).

### *Integrating Palliative Care in the ICU: The Nurse in a Leading Role*

Published in *Journal of Hospice & Palliative Nursing*, this article discusses the key role nurses play in integrating palliative care as a component of intensive care for all critically ill patients. The article reviews the contributions of nurses to implementation of ICU safety initiatives, and how this model can be applied to ICU palliative care integration. To download, go to [bit.ly/1DSYCAS](http://bit.ly/1DSYCAS).

### *Intervention to Improve Care at Life's End in Inpatient Settings: The BEACON Trial*

In this *Journal of General Internal Medicine* article, the authors discuss that "the keys to excellent end-of-life care are recognizing the imminently dying patient, communicating the prognosis, identifying goals of care, and anticipating and palliating symptoms." To download, go to [bit.ly/1MbcRFT](http://bit.ly/1MbcRFT).

### *Ethical Concerns in the Management of Critically Ill Patients*

This chapter from SCCM's *Comprehensive Critical Care: Adult* textbook introduces principles of ethics, how to decide what is ethical, and then addresses treatment of patients in the ICU which includes consent for treatment, decision making, and withdrawal or withholding treatment. To access, go to [bit.ly/1dyaxgs](http://bit.ly/1dyaxgs).

### *Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009*

The authors in this *JAMA* article conclude that "between 2000 and 2009, the ICU utilization rate, overall transition rate, and number of late transitions in the last 3 days of life increased." To download, go to [bit.ly/1A0O8GO](http://bit.ly/1A0O8GO).

## Patient Resources

### *The Problem of Hubris*

Dr. Atul Gawande, author of *Being Mortal: Medicine and What Matters in the End* addresses the limitations of society and health care in attempting to solve the “problem” of aging and dying in this BBC Reith lecture series. In *Being Mortal* as well as in this lecture series, Dr. Gawande examines how “medicine has triumphed in modern times, transforming the dangers of childbirth, injury, and disease from harrowing to manageable. But when it comes to the inescapable realities of aging and death, what medicine can do often runs counter to what it should.” To listen, go to <http://bbc.in/2b8ZOKc>.

### *The Fallacy of ‘Giving Up’*

This article, featured in *The Atlantic*, details “the importance of talking with a doctor about values and priorities in life—at any age.” The author notes how Dr. Gawande’s *Being Mortal* and another recently published book, *The Conversation* by Dr. Angelo Volandes, as well as *How We Die*, a book written twenty years ago by Dr. Sherwin Nuland are evidence end-of-life discussions have “grown extremely loud inside of the health-professional echo chamber, but is somehow still only faintly reverberating into broader culture.” To download, go to <http://theatlantic.com/2016/08/22/2b8Zxqh>.

## Palliative Care

### *What Should You Know About Palliative Care?*

This handout from CAPC addresses what palliative care is, where it is received, who provides it, what to expect and how to get started. To download, go to [bit.ly/1cC483e](http://bit.ly/1cC483e).

### *Palliative Care Glossary*

Developed by CAPC, this resource explains commonly used words, phrases and acronyms to assist patients to better engage in their care. To download, go to [bit.ly/1EZRG41](http://bit.ly/1EZRG41).

### *Palliative and Hospice Care: Comfort during a Serious Illness or the Final Months of Life*

This handout from NHPCO provides answers to frequently asked questions for patients to use when talking with health care providers. To download, go to [bit.ly/1Kf3gjJ](http://bit.ly/1Kf3gjJ).

## Advance Directives

### *Put It in Writing*

This AHA resource provides basic facts about advance directives and encourages patients to explore their preferences for care at the end-of-life. Documenting wishes, putting them in writing, empowers patients to make decisions on their terms. To download, go to [bit.ly/1GoUj6R](http://bit.ly/1GoUj6R).

### *Conversation Starter Kit*

Created by the Conversation Project and the Institute for Healthcare Improvement, this starter kit guides conversations for end-of-life care among families. “Too many people die in a manner they would not choose, so The Conversation Project offers people the tools, guidance and resources they need to begin talking with their loved ones, around the kitchen table, about their wishes and preferences.” To download, go to [bit.ly/1djBogd](http://bit.ly/1djBogd).

## CaringInfo

NHPCO’s website for patients provides information and support to plan ahead, when caring for a loved one living with an illness or grieving a loss. To access, go to [bit.ly/1Ld8lJz](http://bit.ly/1Ld8lJz). One section provides resources for advance care planning, including:

- Communicating Your End-of-Life Wishes
- What to Do If Family Members Disagree
- How to Talk with Your Health Care Providers

## ICU and Treatment

### *MyICUCare.org*

The SCCM website for patients and families offers resources such as:

- Making Decisions about ICU Care
- Participating in Care: What Questions Should I Ask?
- Taking Care of Yourself While a Loved One Is in the ICU
- What Are My Choices Regarding Life Support?

### *Artificial Nutrition and Hydration at the End-of-life*

In order to empower patients and loved ones to make an informed decision, this NHPCO document provides answers to questions such as when artificial nutrition and hydration are used, why, and what it means to refuse or withdraw such interventions. To download, go to [bit.ly/1SPqnRR](http://bit.ly/1SPqnRR).

