

Integrating Palliative Care in Oncology Practice:

Building Better Bridges to Quality of Life

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EVP Healthcare Quality and Value



National Patient
Advocate Foundation

COA Annual Community
Oncology Conference
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Disclosure



Rebecca Kirch is a consulting advisor to the Center to Advance Palliative Care.

Objectives

- 1) **Define** palliative care and its impact on quality of life and person-centered care delivery
- 2) **List** key research studies that have demonstrated the benefits of palliative care in oncology
- 3) **Explain** the value proposition for palliative care in the triple aim context of better health and better care at lower cost
- 4) **Identify** the critical components of palliative care in delivery of high quality oncology services
- 5) **Locate** at least three available resources for improving core palliative care competencies that support person-centered care
- 6) **Describe** at least five action steps that support person-centered and family-focused quality oncology care improvement in this era of value-based reform

Quality is our Context

Modern medicine has helped thousands of seriously ill adults and children live longer lives.

Value-based care demands that we bring the same level of attention to the *quality* of these longer lives.



Today's session emphasis

- *Science behind palliative care integration*
- *Words to use and integration approaches in practice*
- *Communication resources available*
- *Advocacy and Action steps we can all pursue*

Pressure Points: Better Patient Experience at Lower Cost



Demand for value-based care is growing. Success depends on:

Attention to the **Patient Experience**

- Assessment and treatment of pain, depression, other symptoms and suffering patients/families identify as important
- Caregiver needs for information and support

Efficient **Health Services Utilization**

- Reduced ED and hospital use
- Keeping costs below target

Amy

“I don’t want longer length of life if it is a bad time.
I want a **good time** for as long as possible.”

*“Palliative care is
the best friend of
the seriously ill.”*



Berman A, Living Life In My Own Way—
And Dying That Way As Well
(Health Affairs April 2012)

Berman A, The Next Chapter: Amy Berman
Reflects on ‘Living Life in My Own Way’
(Health Affairs Blog May 2014)

What Hospital and Health System Leaders Say

Top Challenges They Face:

- Insurance Reimbursement
- Patient Satisfaction
- Hiring and Maintaining Staff

Benefits of having a PC program:

- Improves QOL and support for patient and family
- Improves doctor and staff satisfaction

Education and resource needs:

- **Patients** need to be made aware that PC exists as an option
- **Providers** need PC training and help understanding that people benefit from PC earlier in treatment than they might think
- **Executives** need to understand the value and benefits of PC for their institution

Source: CAPC 2017 market research among health system leaders across the US about providing care for seriously ill patients

Palliative Care = Triple Aim Solution

- **Improves quality of life**

- ✓ Relieves pain, distress, uncertainty
- ✓ Addresses patient and family goals

- **Strengthens communication**, decision-making and family satisfaction/well-being

- **Coordinates medical and practical needs** across care settings and care transitions

- **Reduces resource utilization and costs** by matching treatment to patient and family goals

- Makes it more likely that adults, children and families have **fun and meaning**



Early palliative care *delivers a better patient experience*

- Dramatic reduction in depression (16% vs. 38%)
- Higher quality of life score (98.0% vs. 91.5%)
- *Increased survival by 2.7 months*



Temel JD, Greer JA, Muzikansky A, et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer, *New England Journal of Medicine*. 2010;363(8):733-742.

Also shown to *improve caregiver experience*

Kavalieratos D, Corbelli J, Zhang D, et al. Association between palliative care and patient and caregiver outcomes: A systematic review and meta-analysis. *JAMA*. 2016;316(20):2104-2114.

El-Jawahri A, Greer JA, Pirl WF, et al. Effects of Early Integrated Palliative Care on Caregivers of Patients with Lung and Gastrointestinal Cancer: A Randomized Clinical Trial. *The Oncologist*. 2017.

What's in the syringe?

Three elements of PC visit focus associated with *improved patient outcomes*:

Defining the Elements of Early Palliative Care That Are Associated With Patient-Reported Outcomes and the Delivery of End-of-Life Care

[Michael Hoerger](#) , [Joseph A. Greer](#), [Vicki A. Jackson](#), [Elyse R. Park](#), [William F. Pirl](#), [Areej El-Jawahri](#), [Emily R. Gallagher](#), [Teresa Hagan](#), [Juliet Jacobsen](#), [Laura M. Perry](#), and [Jennifer S. Temel](#)

- **Coping:** Improved QOL and reduced depression symptoms
- **Treatment Decisions:** Reduced chemotherapy initiation and hospitalization in 60 days before death
- **Advance Care Planning:** Increased likelihood of using hospice

These are **key elements of early PC** to enable dissemination of the integrated care model.

Early palliative care *delivers cost savings*

- Early palliative care shifts expenditures from inpatient to outpatient and hospice
- Over \$2,500 saved per case

Greer JA, Tramontano AC, McMahon PM, et al. Cost Analysis of a Randomized Trial of Early Palliative Care in Patients with Metastatic Nonsmall-Cell Lung Cancer. *J Palliat Med.* 2016;19(8):842-848.

Early palliative care *controls utilization*

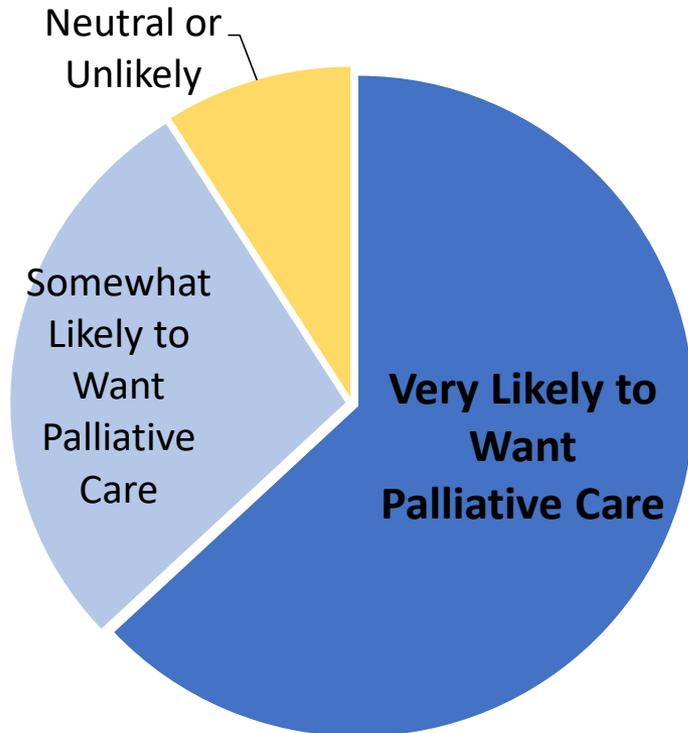
Early versus late referral to palliative care for decedents:

- Reduced hospital admissions (33% vs. 66%)
- Reduced ED use (34% vs. 54%)
- Reduced ICU use (5% vs. 20%)

Scibetta C, Kerr K, McGuire J, Rabow MW. The Costs of Waiting: Implications of the Timing of Palliative Care Consultation among a Cohort of Decedents at a Comprehensive Cancer Center. *J Palliat Med.* 2016;19(1):69-75.

People WANT Palliative Care

Once Informed, People Are:



Key consumer research takeaways:

- Palliative care is a relative unknown among **consumers** (92% really don't know what it is)
- People understand and want palliative care if we **use their words** to define & describe it
- Use consistent QOL messages proven to work and they will stick

Data from CAPC/ACS Public Opinion Strategies national survey of 800 adults conducted June 2011. www.capc.org

Palliative care = quality care

“It’s like when you’re filling in concrete.

The transplanters are the people who put the layer down, then palliative care are the people who go after and fill the holes, so the whole thing doesn’t start to crumble.

But if it does start to crumble they’re the people who actually go with the hard hats and fix it.”

- Gwen Lorimer, *The New Yorker* Jan 2014



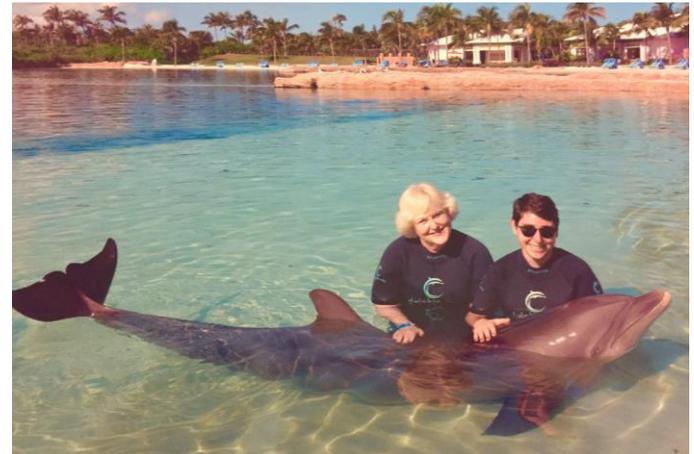
“If you ever have any doubt about the value of this program, believe me, there are families that I’ve met, and two minutes into that conversation, for you to say there’s not value in palliative care would be impossible.”

- Akron Children’s Hospital CEO Bill Considine

QOL Lifeline

Palliative care improves:

- **Quality of life** and the quality of how people are *living*
- **Care coordination** over the course of illness
- **Communication** about what matters most to patients and families that helps match treatment with their values
- **Quality of care** that helps patients and families avoid 911 calls, ED visits, repeated lengthy hospitalizations



Who delivers it? All Clinicians

Palliative Care Specialists

Specialized team consultation/co-management:

- High ED use
- Complex decisions
- Challenging symptoms
- Poor Adherence
- High caregiver distress

These are the patients that would benefit from palliative care consults and/or co-management

Generalist palliative care: Everyone

Basic symptom management, communication and coordination to align treatment with goals and support quality of life

Evidence-based skills training is readily available for all oncology clinicians

Payment for palliative care services

Two palliative care APMs recently recommended by PTAC advisory panel to HHS



<https://www.capc.org/payers/palliative-care-payer-provider-toolkit/>

In the meantime...

- **Hospitals** bill for inpatient days under traditional Medicare/Medicaid or commercial insurance
- **Physicians** (and APNs in some states) bill for consultation services under Medicare Part B and commercial insurance
- **Direct funds** and **philanthropy** cover the gaps
- **Medicare** has 2 advance care planning codes

The Oncology Care Model

OCM participation means oncology teams must conduct:

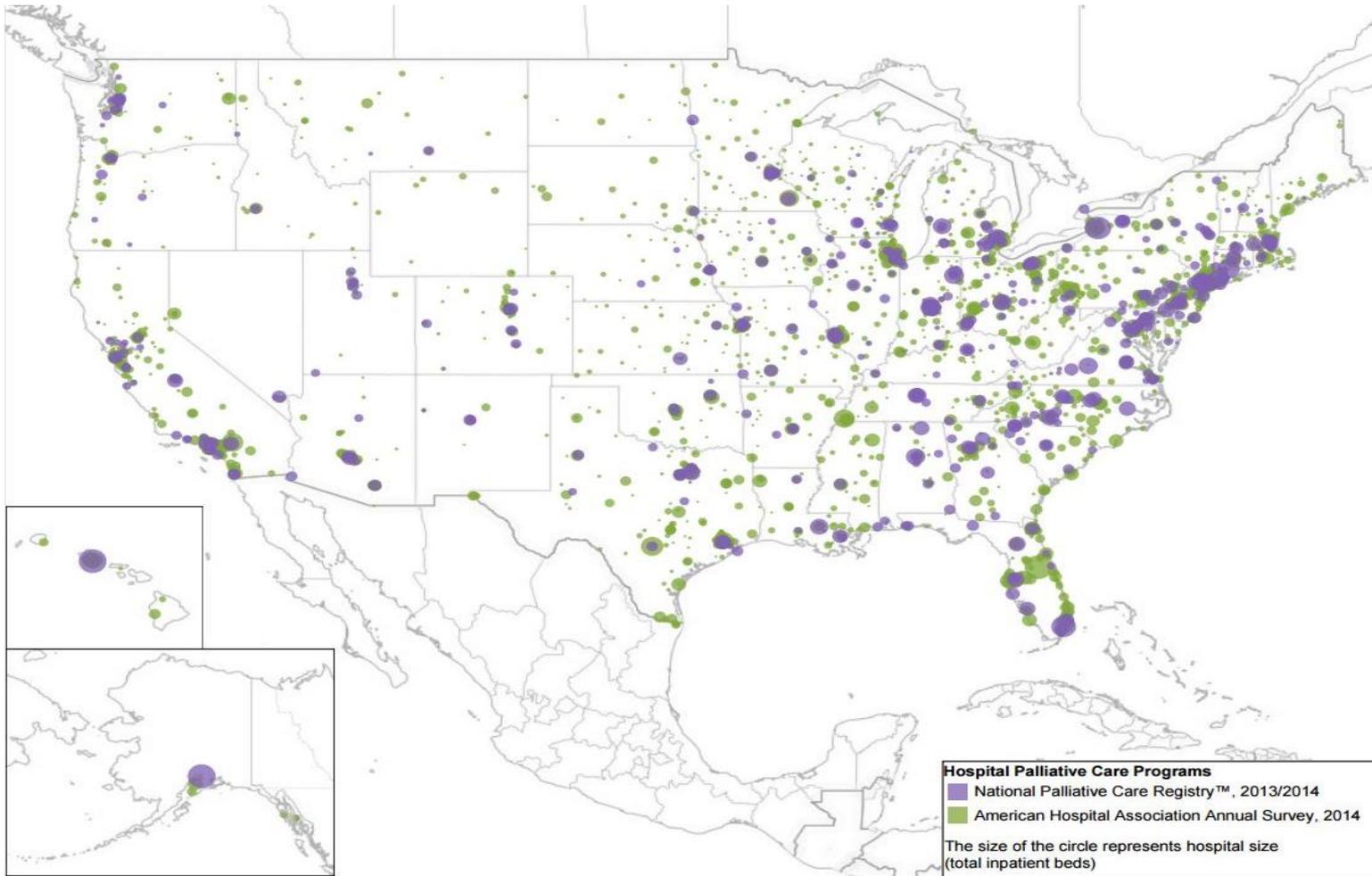
- **Expert and effective pain and symptom management** (the #1 reason for 911 calls);
- **Skilled communication** about achievable and affordable priorities for care
- **Coordination** over time and across settings

OCM “enhanced services” require 13-point care plan that communicates:

- Treatment benefits and harms, toxicities, short term and late effects
- QOL and likely experience with treatment
- Who will take responsibility for specific aspects of patient’s care

Palliative care integration in oncology is essential for improved quality care.

Many practices already have access to palliative care specialists



www.getpalliativecare.org

Some cancer centers are embedding palliative care teams into their practice



Palliative Care Improves Value

Improves Quality

- Symptoms
- Quality of life
- Family satisfaction
- Family bereavement outcomes
- Clinician satisfaction
- May improve length of life



Shrinks avoidable spending

- Need for hospital, ICU, ED
- Hospital costs
- 30 day readmissions
- Hospitality mortality
- Labs, imaging, pharmaceuticals

Optimal Care: Survival with QOL

Even cancer patients with relatively good prognoses have **significant symptom burdens** in physical, emotional, and existential domains

Comparing Symptom Burden in Patients with Metastatic
and Nonmetastatic Cancer

Journal of Palliative Medicine December 2015

Yunie Kim, MD, Irene H. Yen, PhD, and Michael W. Rabow, MD

Palliative care needs of *all adults and children* confronting cancer must be assessed and addressed in all care settings – regardless of disease stage or prognosis.

Optimize longevity and well-being

Extend survival

with high quality of life



Early Specialty Palliative Care — Translating Data in Oncology into Practice. Parikh RB, Kirch RA, Smith TJ, Temel JS. *New England Journal of Medicine* 2013

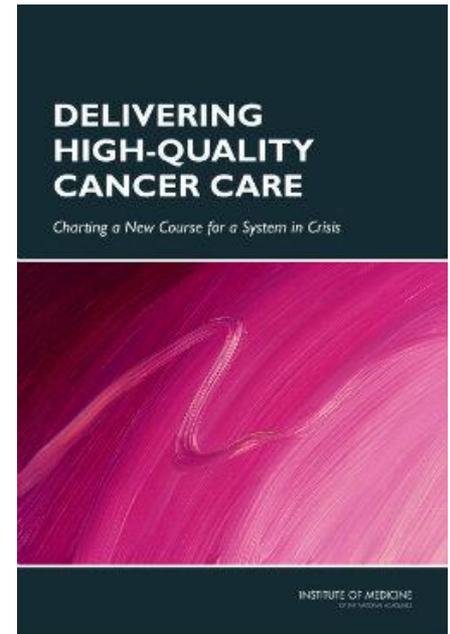
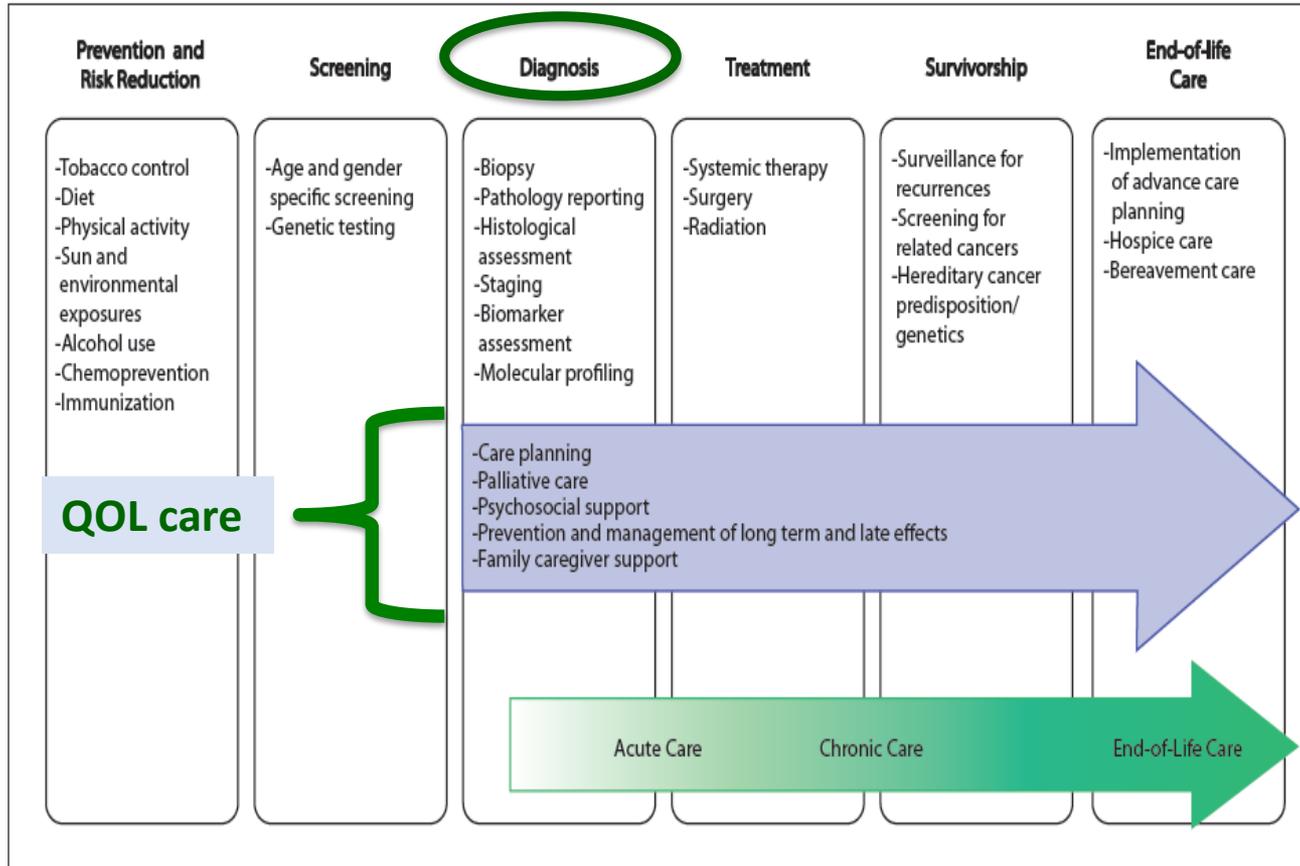
Advancing a Quality-of-Life Agenda in Cancer Advocacy: Beyond the War Metaphor. Parikh R, Kirch R, Brawley O. *JAMA Oncology* 2015

Integrating the patient and caregiver voice into serious illness care: Proceedings of a Workshop. *National Academies of Sciences Engineering and Medicine* 2017. www.nap.edu.

Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine Workshop highlights and next steps. Kirch R, Reaman G, Feudtner C, et al. *CA: A Cancer Journal for Clinicians* 2016

Cancer rehabilitation and palliative care: critical components in the delivery of high-quality oncology services. Silver J, Raj V, Fu J, Wisotzky E, Robinson Smith S, Kirch R. *Supportive Care in Cancer* 2015

Consensus on quality care elements



Institute of Medicine Quality Cancer Care Report:
Charting a New Course for a Health System in Crisis (2013)

ASCO 2016 Clinical Practice Guidelines

*Inpatients and outpatients with advanced cancer should receive dedicated palliative care services early in the disease course **concurrent with active treatment.***

*Referral of patients to interdisciplinary palliative care teams is optimal and **services may complement existing programs.***

Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services.

Pediatric Patients

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

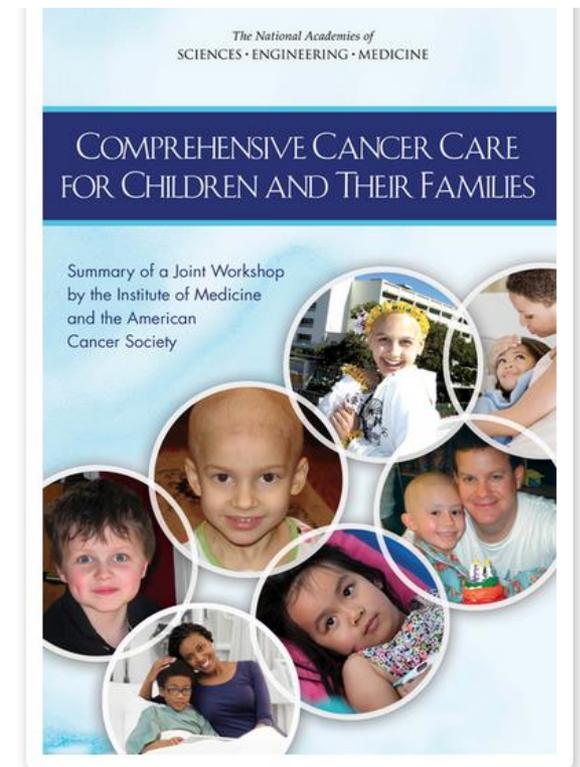


AAP Policy Statement 2013 also called for pediatric palliative care as an **essential aspect of providing optimal treatment** from diagnosis and continuing along course of care

But...

- **Only 58%** of COG member institutions have a pediatric palliative care service
- **Nearly one-third** of children's hospitals still don't have a palliative care program
- **Most** pediatric palliative care programs are understaffed

(Feudtner et al. Pediatrics 2013)



ASCO and AAHPM Joint Statement

Guidance on Defining and Providing High-Quality Palliative Care Services in Oncology

Oncologists: All Patients

Assess and manage symptom burden
Explain prognosis
Ask about what's most important
Review all treatment options

Palliative Care Consults: Complex Patients

Co-manage complex or intractable symptoms
Help clarify priorities for care
Address caregiver distress, social challenges
Maximize quality of life

Hospice Referral

Discuss when disease progresses despite treatment

Mission Critical: Quality of Life and Person-Centered Communication



“I think it is very important for everybody to be honest with families, to tell you what is going to happen. *This is how you can prepare.*”

Then your *hope can change* along with the circumstances.”

- With the doctors there was not really much balance as far as quality of life.
- They were very concerned with curing - it was his cancer they wanted to treat and not him.
- The nurses, *they saw my dad.* And they saw a family who was grieving and needed help.

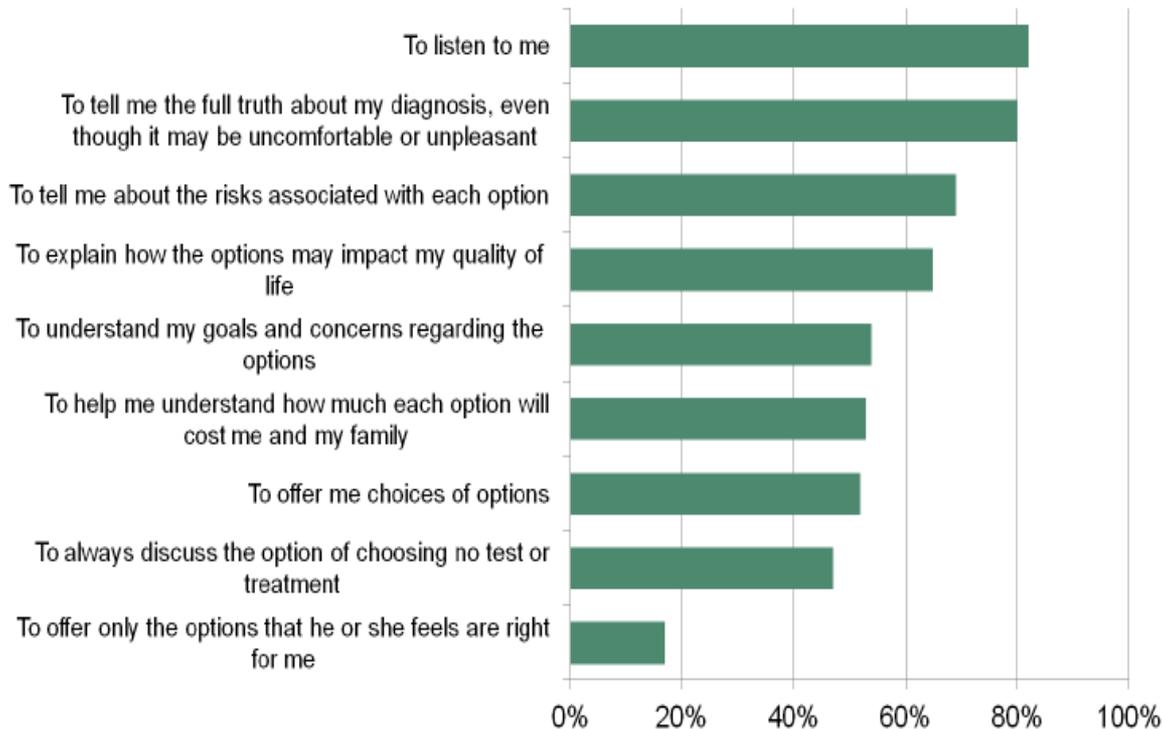
[Palliative care and quality of life: patient-centered care case study.](#)
Kirch R. *Archives of Internal Medicine* 2012; 172(15):1170-1172.

[Patient Advocate Foundation Roadmap to Consumer Clarity Report](#)
Case Study 2017. www.npaf.org

Patient and Family Priorities

Figure 1. People want involvement in evidence and decisions

Bars show the percent of people surveyed who strongly agree with the statement: "I want my provider..."



What people want
(n=1068 adults):

- **Listen to me**
- **Tell full truth**
- **Tell about risks**
- **Explain impact on QOL**
- **Understand my goals and concerns**

IOM 2013 Quality Cancer Care report: Charting a New Course for a System in Crisis

Alston C, Paget L, Halvorson GC, et al., Communicating with patients on health care evidence: Discussion paper (2012)

<https://nam.edu/wp-content/uploads/2015/06/VSRT-Evidence.pdf>

Making Person-Centered Care Happen

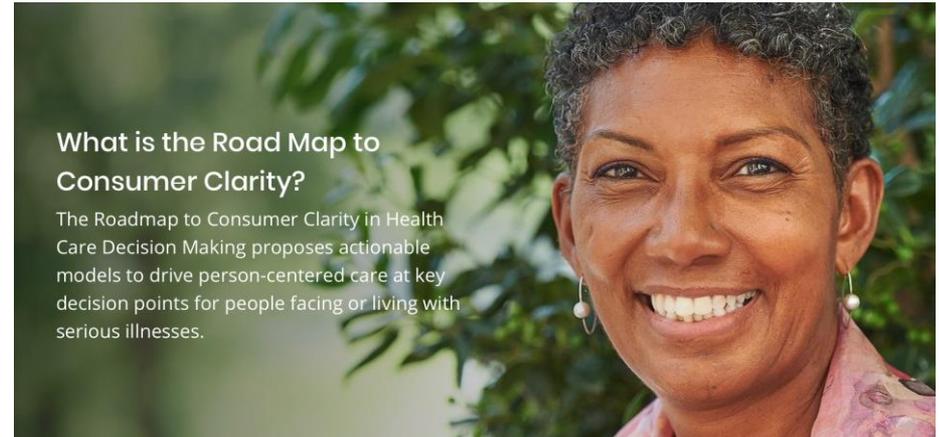
Knowing what's important to patients and caregivers is paramount.

They want:

- Understandable, accurate health care information
- Family-focused care that uses skilled communication to engage them as partners
- Care and services aligned with their priorities and preferences

What matters to them is *essential expertise* they must be invited to bring to the table continuously.

Patient Advocate Foundation's 2017 Roadmap to Consumer Clarity on Health Care Decision Making

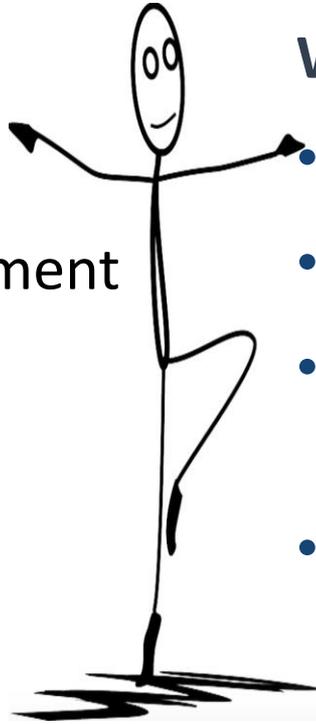


VIEW ROADMAP REPORT AT <https://www.npaf.org/roadmap/>

Rebalancing the Health System

WHAT'S THE MATTER

- Diagnosis
- Disease-directed treatment
- Manage side effects
- Coordinate care and transitions
- Evaluate outcomes



WHAT MATTERS

- Support QOL and function
- Minimize burdens on family
- Address concerns about role changes and illness stigma
- Acknowledge uncertainty, hopes, fears, and spiritual concerns

Person-centered and Family-focused Care

**Skilled
Communication**

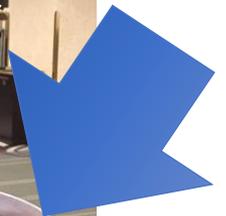
Person-Centered Communication is Palliative Care's Core Competency

QOL Conversation Cues:

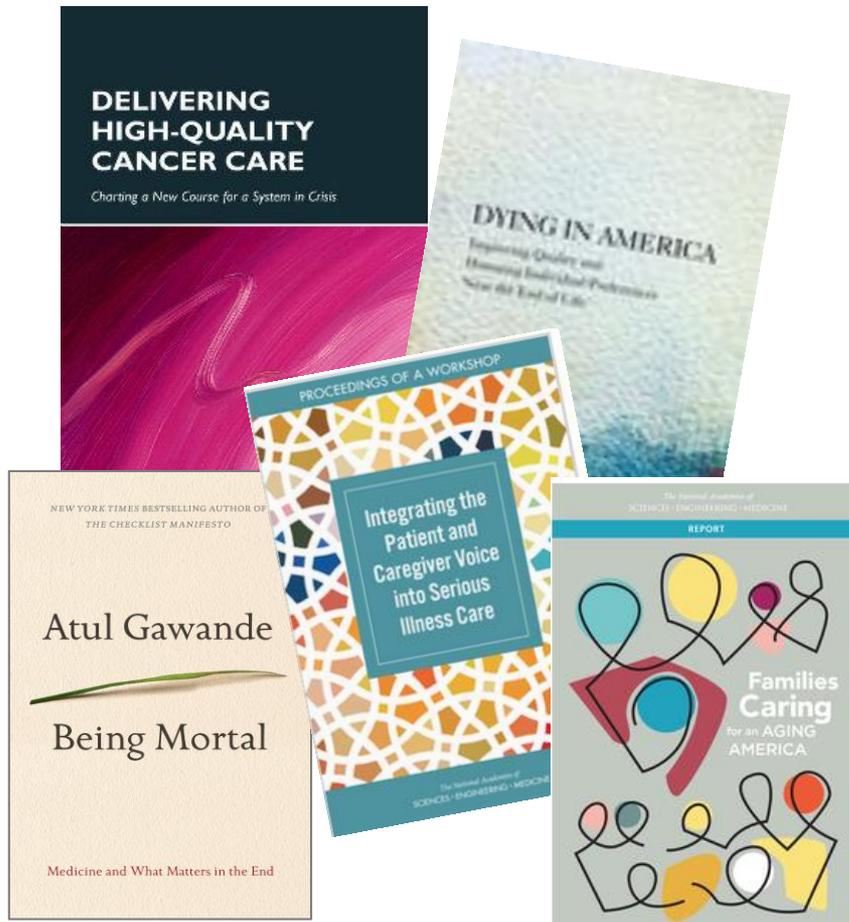
1. Tell me about you as a person
2. How do you like to get medical information?
3. What is your understanding of your situation now?
4. **What is important to you?**
5. What are you hoping for and what are your worries?
6. Where do you find your strength and comfort?



Always Ask
Tattoo
Apply here



Consensus Now: QOL communication is essential in quality care planning and treatment



Recommendation: Provide understandable information about cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and costs

Recommendation: Professional education for cancer programs should *prioritize formal clinical communication skills development training*

Explainaholicism

Empathy



Anthony Back, MD

Expect Emotion.

**TIP: If you feel compelled to respond with a fact,
*hit your pause button***

Launch of the Communication Skills Pathfinder (Open to All)

Thursday, April 19, from 1:00 - 2:00pm ET



Register at www.capc.org

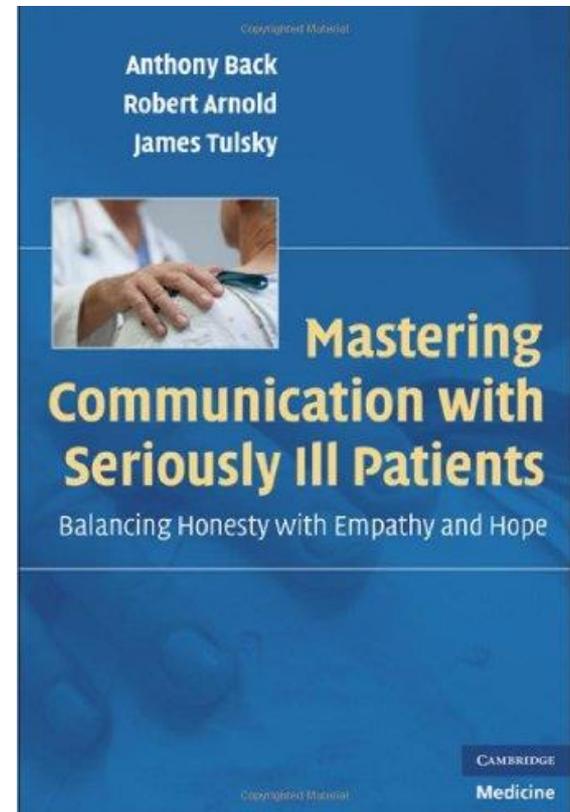
Practicing empathy works!

Good communicators draw on a large repertoire of learned skills to collect essential **person-centered data about their patient's values, goals and concerns.**

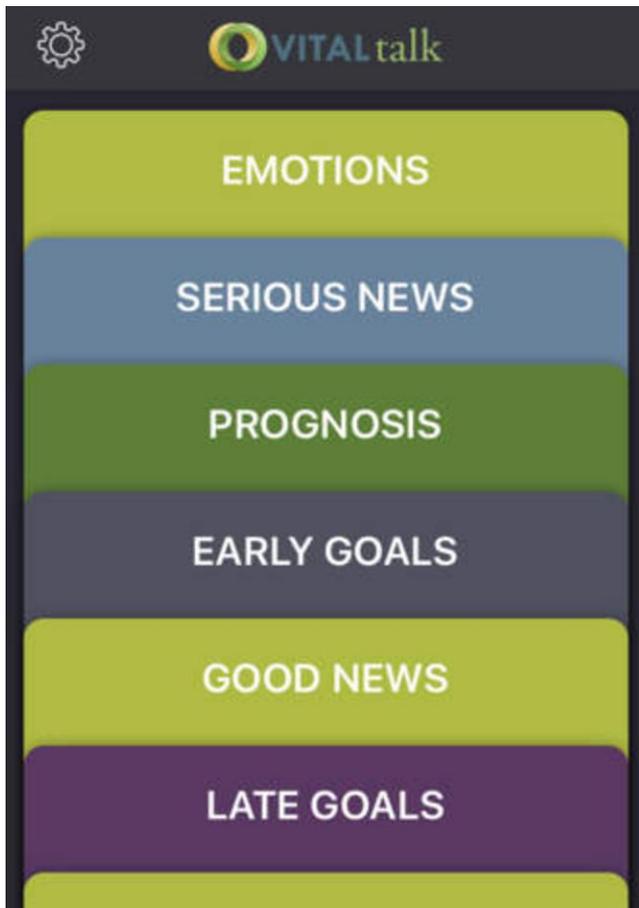
These skills take practice to master.

Good communication promotes **patient trust** plus professional resilience that **prevents burnout.**

Rx: This book is a superb starter course to hone clinical communication skills for handling tough conversations



High-quality, evidence based communication training is ready



- ✓ Talking maps and podcasts vitaltalk.org
- ✓ iPhone/Android APPS **VitalTalk and VitalTips**
- ✓ Online course and in-person training vitaltalk.org/courses
- ✓ VitalTALK online communication curriculum is also available through [CAPC Central](https://capc.org) at capc.org

Center to Advance Palliative Care (CAPC)

CAPC provides hospitals, health systems, hospices, payers, and other health care organizations with the **tools, training, technical assistance, and metrics** needed to support the successful implementation of palliative care.

Over 1,000 hospitals and health systems are members and all staff have access to CAPC resources

- Communication skills
- Pain Management
- Symptom Management

www.capc.org



Professional Webinar Series 2017



Palliative Care, Value-Based Payment and the Patient Experience: A Guide for a Changing World

Featuring Diane Meier, MD, Director, Center to Advance Palliative Care



Matching Treatments to Values: Sharpening Person-Centered Communication Skills and Strategies

Featuring Anthony Back, MD, Professor of Medicine at the University of Washington and Fred Hutchinson Cancer Research Center



Solutions in a Time of Crisis: Ensuring Safe and Effective Pain Relief through Good Policy and Practice

Featuring Judith Paice, PhD, RN of Northwestern University and Robert H Lurie Comprehensive Cancer Center and Robert Twillman, PhD, FAPM of the Academy of Integrative Pain Management

Recordings available at: www.npaf.org/our-work/webinars/



Tools for your patients



Welcome

View the PREPARE Pamphlet

- 1 Choose a Medical Decision Maker
- 2 Decide What Matters Most In Life
- 3 Choose Flexibility for Your Decision Maker
- 4 Tell Others About Your Wishes
- 5 Ask Doctors the Right Questions

Your Action Plan

Hide Menu

Welcome to PREPARE!

PREPARE is a program that can help you:

- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.

Click the NEXT button to move on.

Online patient decision support tool at:
prepareforyourcare.org



COURAGEOUS PARENTS NETWORK

Empowering parents caring for children with life-limiting illness.

**Online video library and tools at:
courageousparentsnetwork.org**

**GET PALLIATIVE
CARE**

Consumer-oriented information at:
getpalliativecare.org

Give People the Words to Use



Good Conversations
Start with “Hello” ...

- Patients
- Clinicians/staff
- Community Education



COMMON PRACTICE

Rx: Playing this game creates a safe place to talk about what’s important to people, transforming anxiety about dying into *conversations about living*

Access info at <http://www.commonpractice.com/hello>



Trending: Palliative Care as Standard of Practice

“Palliative care is the entity that comes forward and asks the right questions. I’m not saying other staff won’t come to the fore and make everything ok, but boy, **palliative care is an insurance policy and I don’t know how a hospital would meet their mission without having that service.**”

– *CEO Bill Considine, Akron Children’s Hospital*

“There’s a strong rationale for hospital investment in PPC because it fosters effective communication, enhances quality care, and improves the patient and family experience – **this really is an investment in delivering high quality care.**”

– *CHOP Physician-in-Chief Joe St. Geme*

“Regardless of whether it generates a lot of revenue, it’s just mission critical. Families need it, critically ill children, children with chronic disease, children with complex medical problems, they all need it. It’s absolutely essential to their recovery, to their health, in some cases to death with dignity. It’s one of those ‘gotta do’ things. **It’s not optional. It’s mandatory.**”

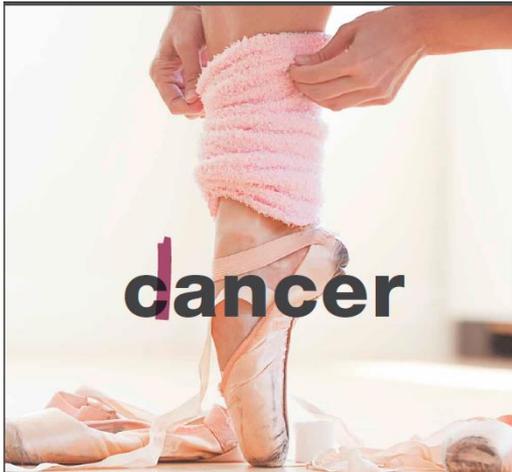
– *Texas Children’s Department Chair Mark Kline*

National Strategy for Boosting PC Access

What will it take?

- **Increase awareness** of PC benefits for public, professionals and policymakers
- **Expand education** for health care workforce
- **Provide adequate training** and support for care team - including family caregivers
- **Align reimbursement** and insurance design to match patient/family needs
- **Improve accountability** for quality
- **Boost research investment** to build the evidence base

Treating the person beyond the disease



dancer

Palliative care sees the person beyond the cancer treatment. It gives the patient control. It brings trained specialists together with doctors and nurses in a team-based approach to manage pain and other symptoms, explain treatment options, and improve quality of life during serious illness. Palliative care is all about treating the patient as well as the disease. It's a big shift in focus for health care delivery—and it works.

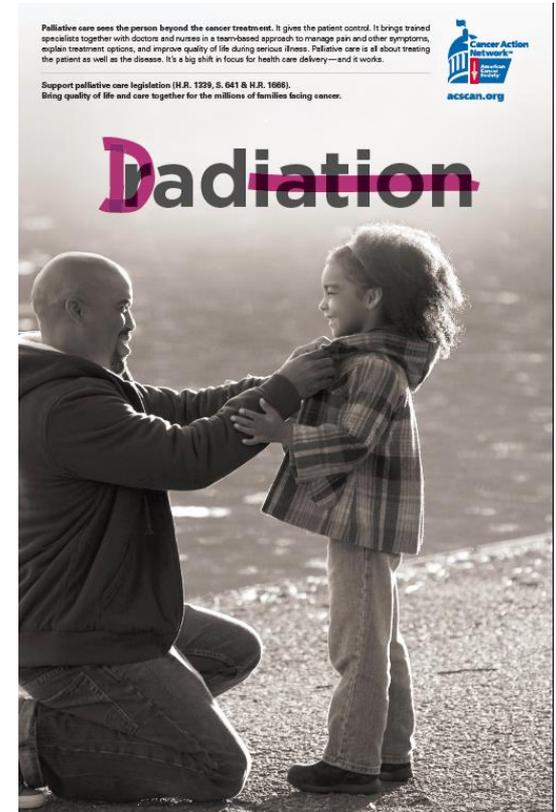
Support palliative care legislation (H.R. 1339, S. 641 & H.R. 1666). Bring quality of life and care together for the millions facing cancer.



chemotherapy

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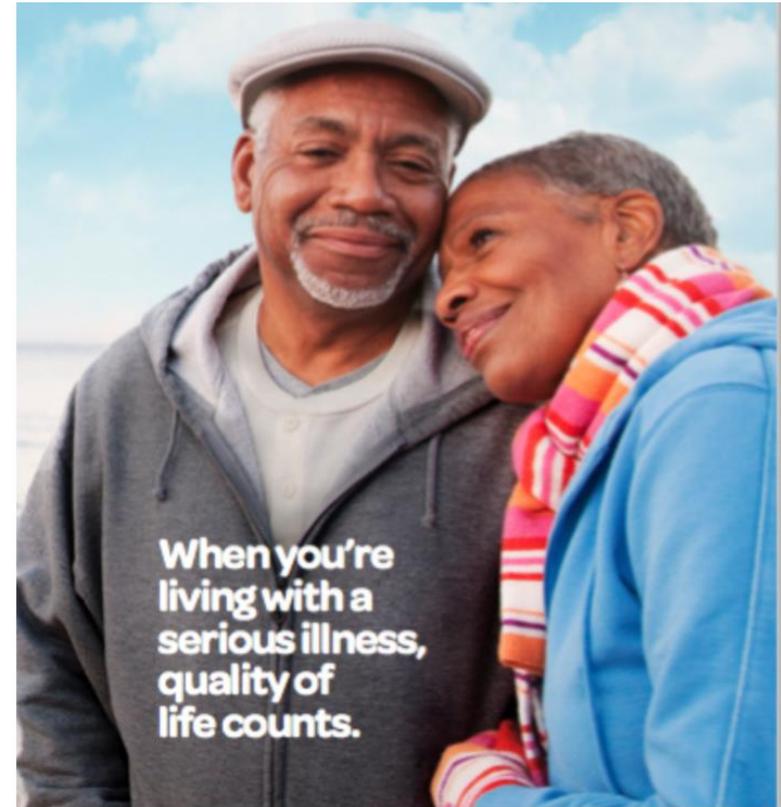
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Dadiation



Patient QOL Coalition Activity



Support PCHETA (H.R. 3119/S. 2748) to help patients live better.

The PCHETA bill increases access to palliative care—a team-based approach designed to help manage pain and other symptoms, explain treatment options, and ultimately give patients more control over their care. Passing the bill could improve quality of life for millions of Americans. Learn how at patientqualityoflife.org.



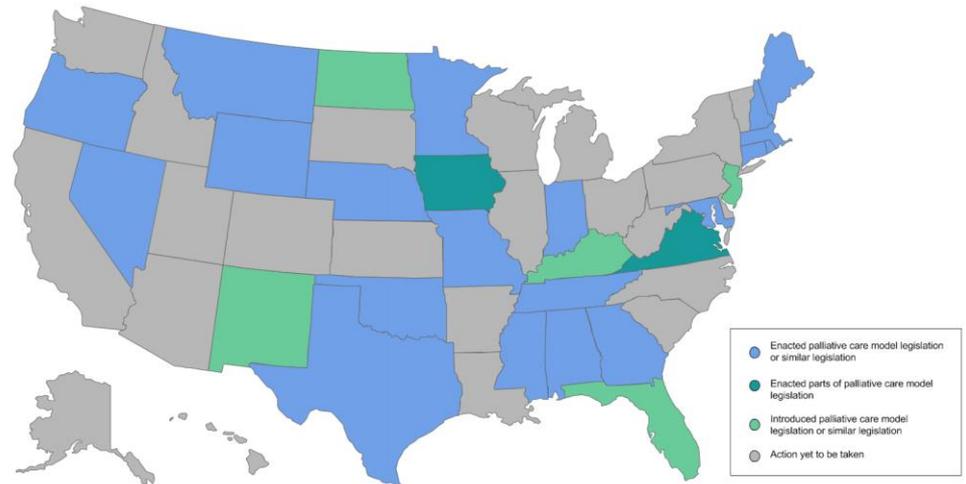
Palliative Care National Legislative Agenda

Palliative Care & Hospice Education and Training Act (PCHETA) H.R. 1676 & S. 693

- Promote education and research
- Increase public awareness
- Support development of faculty careers in academic palliative medicine
- Increase palliative care faculty in medical, nursing, social work schools

State palliative care legislation

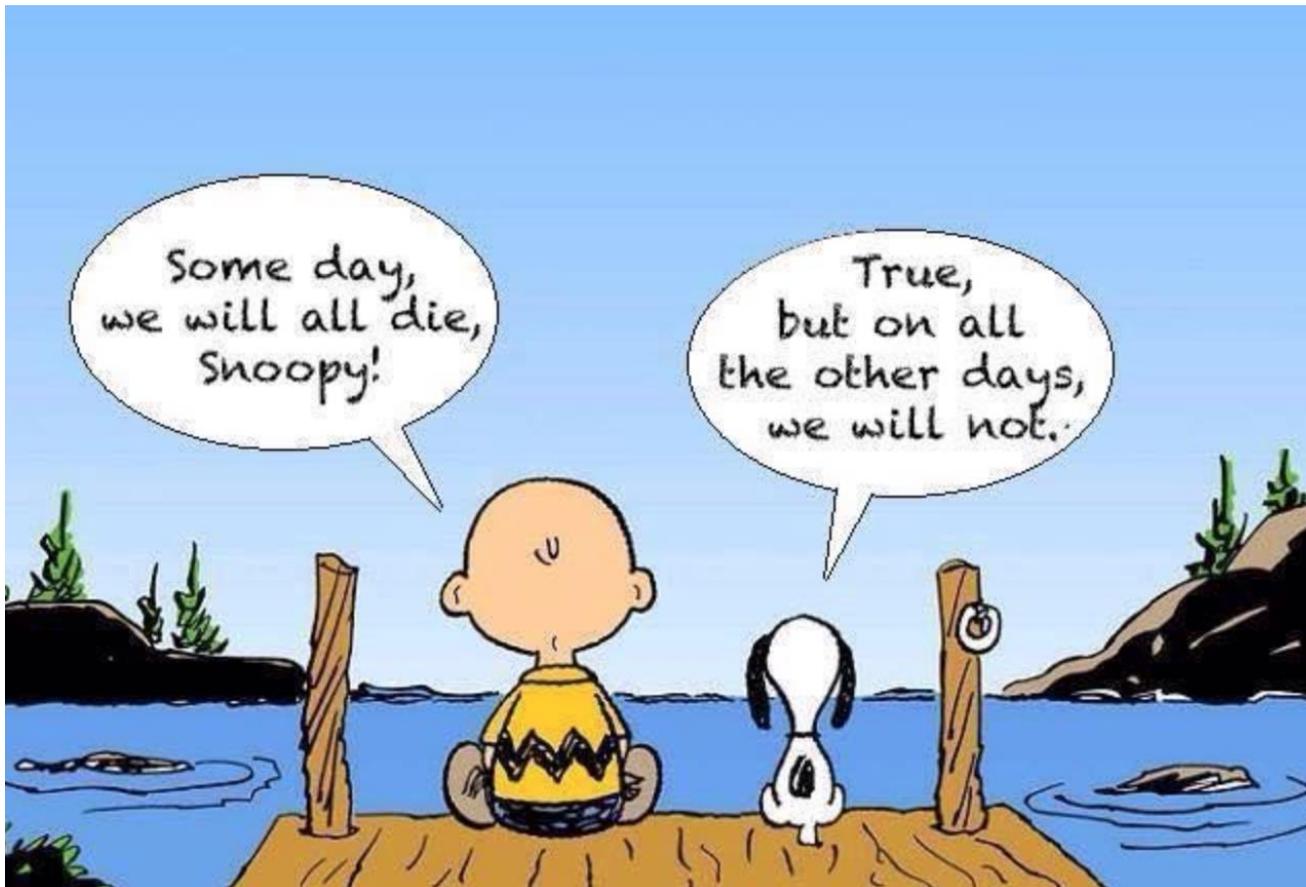
- State expert advisory council
- Information and resources for consumers and clinicians



Educate. Energize. Engage.

Achievable Actions to Deliver Real Value

- ❑ **Ask what matters to patients and caregivers** at key points and document those priorities so they get the quality care they want
- ❑ **Talk about palliative care as standard of practice** for all audiences – it's an added layer of support for maximizing QOL and quality care
- ❑ **Get to know palliative care colleagues** at your institution
- ❑ **Check out the noted resources** and tell colleagues about them to help boost person-centered communication skills and care
- ❑ **Prioritize person-centered communication** and practice empathy – try the “Always Ask” tattoo
- ❑ **Commit to skills development training**
 - ✓ Register for the 4/19 Communication Skills Pathfinder webinar
 - ✓ Find out if your institution has a CAPC membership to access online curricula
 - ✓ Subscribe to VITALtalk
 - ✓ Play “Hello” with your family/friends/team



NPAF

National Patient
Advocate Foundation

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