

How Clinicians Can Influence Public Perception of Palliative Care

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Center to
Advance
Palliative Care™

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Message Lab

Why This Matters

Perception is the Gatekeeper to Access

Palliative care is plagued by misunderstanding

ALDEBRA SCHROLL, MD | PHYSICIAN | JULY 26, 2024



During a recent palliative conference, the discussion turned to the challenges of translating our work to the public and our colleagues. Despite the growth of our field and increasing access, there remains major confusion about palliative care and hospice. Much of the misunderstanding originates from within the medical profession. Having worked in the palliative care and hospice arena for nearly two decades, I have seen many examples of the confusion and fear of our field.

A common response to a palliative care recommendation is, "They're not ready for that yet." However, current guidelines are to initiate palliative care services upon the diagnosis of a serious illness. Earlier evaluation allows for time to establish rapport with both the patient and family while keeping quality-of-life considerations in focus. Shared decision-making requires careful dialogues to relay complex medical issues and understand the patient's priorities for their care. This is best done in the context of a relationship.

KevinMD.com

For patients to get palliative care today:

- They have to want it
- Referrers have to believe it's good for their patients (and them)
- Administrators have to believe it's good for patients, clinicians, and the organization

For *more* patients to get palliative care in the future:

- Payers and policymakers have to believe it's high-value and feasible to implement



What does this mean for you?

- ✓ We are all ambassadors for palliative care.
- ✓ This is something that can be done well or poorly.
- ✓ We have data and expert-informed best practices to guide us.

The Payoff for Using Messaging Best Practices

- **Optimize referrals** (# and appropriateness) → Become a service people want!
- **Educate organizational leadership and staff** → Turn gatekeepers into advocates!
- **Give patients a positive association with palliative care** → Research tells us when patients know what palliative care is, they want it!

Why do we need a definition of palliative care?

Because definitions enable us to have a common understanding of a word or subject. They allow us to all be on the same page when discussing or reading about palliative care.

If we use different definitions, we confuse, and then lose, our audiences. Once that happens, patients and families lose access to palliative care. People need to know what palliative care is and why they would want it (i.e., its benefits).

Evidence-Based Definition of Palliative Care

Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses, social workers, chaplains, and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

(CAPC Public Opinion Research, conducted by Public Opinion Strategies (POS), 2019)

Key Takeaway

Don't define something by what it's not. The audience will remember the negative you're trying to distinguish from.

Example: Palliative care is not the same as hospice.

Audience remembers palliative care and hospice

Vs.

Actually, palliative care helps patients have the best quality of life.

Audience remembers palliative care and quality of life



But wait a minute, can we live up to our own definition?

“Appropriate at any stage of a serious illness”

“Specialty-trained doctors, nurses, social workers, and chaplains”

Where We Are...and Where We're Headed

70% of the public doesn't know what palliative care is

Of those who say they do, 60% equate it with end of life



ALL audiences (patients and families, referrers, administrators, payers) know what palliative care is and have a positive perception

Opportunities to Change Public Perceptions of Palliative Care

Clinical Context

- Progress notes / patient's chart
- Interactions with (potential) referrers
- Engagement with organizational leadership
- Patient information materials

Progress Notes / Patient's Chart

- These communicate with both referring providers AND patients
- Include core domains of palliative care to showcase what we do
 - ✓ Symptoms with management plan
 - ✓ Emotional and spiritual support for coping with serious illness
 - ✓ Goals of care assessments
- May include language about the role of palliative care in serious illness and what you will manage for the patient

Interactions with (Potential) Referrers

- Dialogue with referring providers and others providing direct patient care is another way to showcase palliative care in a positive light
- Use your elevator pitch (we'll get there later!) for those who don't know what you do
- Elaborate when necessary
- Go out of your way to make phone calls to referring providers to discuss their patients and the outcome of the palliative care consult
- The #1 way to directly explain what you do is by using a patient example
- Get involved with health system committees

Engagement with Organizational Leadership

- Use patient stories to engage leadership
- Show the value and impact through the story
 - ✓ How did you change quality of care for a patient?
 - ✓ Why should leadership care? What's the impact to the organization?
- Pick a story that highlights the impact on the pain points of the partner (e.g., too many preventable hospitalizations, low satisfaction, readmissions)

Patient Information Materials

- Patient information (e.g., brochures for your program) should outline the key concepts of palliative care but language should match that of the standardized definition.
- Pictures are worth 1,000 words!
- Describe a service a patient would want to have and avoid words that associate palliative care with end-of-life care or hospice



Specialized in-home support during your treatment

Palliative care serves as an extra layer of in-home support when medically appropriate for people diagnosed with a serious illness. Palliative care focuses on managing your symptoms and improving your quality of life while you continue to pursue treatment options with your own doctors.

Get help at any stage of serious illness

You can benefit from palliative care at every stage of serious illness. And in-home support benefits people of all ages, from children to seniors. Palliative care can be especially helpful to people diagnosed with cancer, congestive heart failure, COPD, ALS, Parkinson's disease, Alzheimer's disease, or kidney failure.

Live life to the fullest while receiving treatment for a serious illness.

The onset of a serious illness impacts a family's quality of life in so many ways. Individuals and their caregivers must deal with debilitating symptoms, travel to specialists and labs, comprehend new medical jargon, and make difficult decisions about treatment options. Meanwhile, the fears and anxieties that come with a serious illness can become overwhelming.

We're here to help

Delaware Palliative's compassionate team works side by side with your physician to control the symptoms of your disease, reduce your anxiety, and ensure that you get the best care possible.

Call **302.478.5707** to learn more about Delaware Palliative.

Serving the entire state of Delaware and southern Chester and Delaware counties in Pennsylvania.

Patient and Public Education

- Websites
- Social media
- Press
- Personal interactions and experiences

Describing Palliative Care: More than a Definition

What are we trying to convey? If Nike just used a simple definition, they wouldn't sell any shoes. Same with palliative care.



Do things history could only dream of.

 Just do it.

The **5** Principles: Serious Illness Messaging

1. Talk up the benefits
2. Present choices for every step
3. Use positive stories
4. Invite dialogue, and not just once
5. Invoke a new team

Palliative Care Program Descriptions on Websites

- 50% hospice
- 25% end of life
- 25% life-limiting
- 21% advanced illness
- 15% terminal

Search Terms from "Palliative Care: Do and Don't Say"

Recommended for Use

Living with a Serious Illness

People/Person with a Serious Illness

Quality of Life

Not Recommended for Use

Advanced Illness

Death/Dying

End-of-Life

Hospice

Life-Limiting

Serious Illness Care

Terminal

Sometimes it's an Easy Fix

[Home](#) > [Services](#) > [Palliative Care](#)

Palliative Care

The Palliative Care Service at [REDACTED] is dedicated to the care and comfort of seriously ill patients and their families. Palliative care focuses on symptom and pain management and quality of life issues for adult patients with complex, chronic or terminal illnesses at any stage of the illness.

Patients receive comprehensive interdisciplinary care. Each patient consultation includes a thorough review of the medical history, a physical examination, and a discussion of the symptoms and goals of the patient and their family. Ongoing evaluation and follow-up care is then provided as needed.

Our palliative care team specializes in end-of-life supportive care which may include issues such as pain, nausea, shortness of breath, fatigue, and side effects from medications and treatments. The team also addresses psychosocial issues such as depression, anxiety, disruption of family life and financial concerns. Social work services and spiritual support for the patient and their family is also offered.

A Picture is Worth 1,000 Words

Access photography guidelines in CAPC's Marketing and Messaging Toolkit



Palliative care

Managing daily pain and symptoms can be difficult. [REDACTED] palliative care helps by providing specialized medical care focused on relieving pain, symptoms and stress caused by serious illness for any hospitalized patients, regardless of age.

By providing you with physical, emotional and spiritual support, [REDACTED] helps you live the best possible quality of life through all stages of illness.

We're here to help you, every step of the way

- Navigation of the health care system
- Guidance through difficult treatment choices
- Coordinating care and the care team, including home care services, if needed
- Referrals to community support services after a hospital stay or as your condition changes



End of life/palliative care quiz

They're often used interchangeably, but they're not the same.

 Find a provider

 Find a location

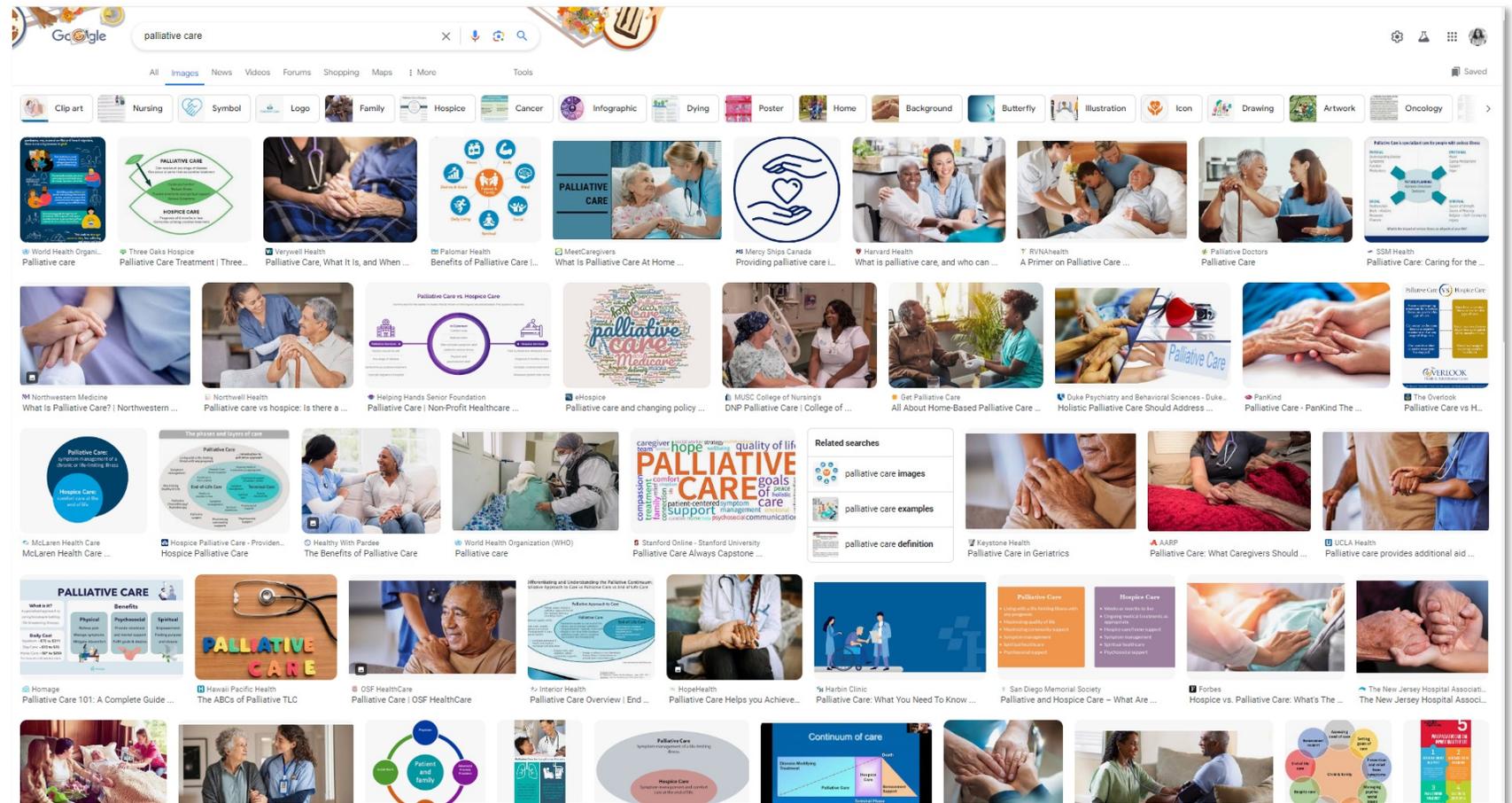
 Request information

In this section

Palliative care

Advanced illness management

Google Image Search for Palliative Care



Talking About Palliative Care on Social Media

Stephanie Harman reposted
 Arif Kamal MD, MBA, MHS
 @arifkamalmd

From the back of the poster walk to the front of the main stage.

Historic day as the @ASCOPres sets the benchmark of palliative care being an indisputable standard of care. #hpc #pallonc



Samantha Winemaker she/her @SammyWinemaker · Sep 25, 2021
 #PalliativeCare is not just specialist care. It is an approach to care, a philosophy of care that all #Doctors & #Nurses can provide. Important not to unintentionally reduce palliative care to specialty care. It's everyone's business. #MedTwitter #MedEd #MedStudentTwitter

CARE Get Palliative Care @GetPalliative · Sep 24, 2021
 If you're wondering what #PalliativeCare is (what it isn't) how it works and how to get it - please read & share our handout.

Let's get correct and accurate information to those who need it.
 ...
 Show more

Palliative Care What You Should Know

Palliative Care (pronounced pali-lee-uh-tiv) is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

- WHERE DO I RECEIVE PALLIATIVE CARE?**
 Palliative care can be provided in a variety of settings including the hospital, outpatient clinic and at home.
- DOES MY INSURANCE PAY FOR PALLIATIVE CARE?**
 Most insurance plans, including Medicare and Medicaid, cover palliative care.
- HOW DO I KNOW IF PALLIATIVE CARE IS RIGHT FOR ME?**
 Palliative care may be right for you if you suffer from pain, stress or other symptoms due to a serious illness. Serious illnesses may include cancer, heart disease, lung disease, kidney disease, Alzheimer's, HEAVY, amyotrophic lateral sclerosis (ALS), multiple sclerosis, Parkinson's and more. Palliative care can be provided at any stage of illness and along with treatment meant to cure you.
- WHAT CAN I EXPECT FROM PALLIATIVE CARE?**
 You can expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. Palliative care helps you carry on with your daily life. It improves your ability to get through medical treatments. It helps you better understand your condition and your choices for medical care. In short, you can expect the best possible quality of life.
- WHO PROVIDES PALLIATIVE CARE?**
 Palliative care is provided by a team including palliative care doctors, nurses and other specialists.
- HOW DOES PALLIATIVE CARE WORK WITH MY OWN DOCTOR?**
 The palliative care team works in partnership with other doctors to provide an extra layer of support for you and your family. The team provides expert symptom management, extra time for communication about your goals and treatment options and help navigating the health system.
- HOW DO I GET PALLIATIVE CARE?**
 You have to ask for it. Just tell your doctors and mention that you would like to see the palliative care team. You can start with the Provider Directory on GetPalliativeCare.org. That's where you can find palliative care in your area, quickly and easily.

4 23 86

Bethel-Divine Health Care Services, LLC
 @betheldivine

Discover the transformative benefits of early palliative care integration. It's more than just symptom management; it's compassionate support for patients and families. Learn how palliative care can enhance your quality of life.

#PikesvilleMD #HomeHealthCare

BETHEL-DIVINE HEALTH CARE SERVICES, LLC

Early Palliative Care Benefits

Early integration of palliative care offers numerous advantages:

- Improves quality of life for patients and families
- Manages symptoms effectively from the start
- Provides emotional and spiritual support throughout treatment

Have Questions? Call Us Today!
443-822-2012
 www.betheldivinehealthcare.com

Palliative Care in the Press

New York Times, March 7, 2019

“As a **palliative care** doctor, I spend much of my time face-to-face with pain and suffering, debilitating disease and **death.**”

DOCTORS

The Lesson of Impermanence

A chance encounter with a sand painting helped me learn how to doctor patients I knew I would lose.



Personal Interactions

Think about talking to people at a dinner party; what do you say when someone asks you what you do for a living?

Tools to Help You Communicate About Palliative Care

Reminder: Evidence-Based Definition of Palliative Care

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(CAPC Public Opinion Research, conducted by Public Opinion Strategies (POS), 2019)

Is the Definition Too Long?

Often the complexity of the description of a term is too great to be captured in a single phrase, image or short sentence.

Example: Coke is a carbonated soft drink flavored with coca leaves, cola nuts, caramel, and sugar.

Develop an Elevator Pitch

- Short and concise speech that introduces yourself and your idea/product/service to a targeted audience
- Explain the concept quickly and spark interest in what you do

“Palliative care helps manage the pain, symptoms, and stress of serious illness to give you a better QOL.”

- You can elaborate on symptoms you treat to match what patient has to have a positive commonality that you can help them!

Tailoring Your Pitch to Your Audience

We have difference audiences:

- Patients and families / caregivers
- Other clinicians
- Organizational leadership



Tailoring the Pitch: Patients and Families

- Palliative care can help manage the pain, symptoms, and stress of serious illness
- The goal is to help you have a better quality of life
- We can also help you with treatment decisions to find the best support and resources for you as you go along



Tailoring the Pitch: Other Clinicians

- Calling in support for patients with complex, time-sensitive needs
- Palliative care can help you with your most complex patients
- We do complicated pain cases and other symptoms such as not eating or drinking, n/v, anxiety/depression
- We do time-intensive discussions to sort out goals of care with patients and families
- I can report back to you when I finish meeting with the patient / family

Tailoring the Pitch: Organizational Leadership

- Outcomes of organizational importance (e.g., reducing hospital LOS)
- Hit the pain points of your organization:
 - ✓ Palliative care can help reduce readmissions and unnecessary hospitalizations by controlling symptoms such as pain that cause patients to frequent the ED
 - ✓ Palliative care can improve the patient experience by offering comprehensive care and multidisciplinary support
 - ✓ Establishing goals of care can help patients navigate the health care system better to get the resources and supports they need to be at home

CAPC Toolkit

MOTIVATE: Marketing and
Messaging Palliative Care

capc.org/MarketingToolkit

MOTIVATE: Marketing and Messaging Palliative Care

Last Reviewed: March 5, 2024



Due to low public awareness and consistent misconceptions, how you frame palliative care and its benefits is vitally important. Marketing, supported by sound messaging, helps patients, families, referral sources, and service partners understand the work that you do. Palliative care is about quality of life. When done well, proper messaging and marketing can clarify this and motivate patients, families, and clinicians to take advantage of it.

Use the MOTIVATE toolkit to refine your program's marketing strategy, and your messaging.

What's in the Toolkit

Messaging Palliative Care



Making the Case for Palliative Care



Audience Research



Designing Your Marketing Strategy



Marketing to Increase Referrals



Serious Illness Messaging Toolkit

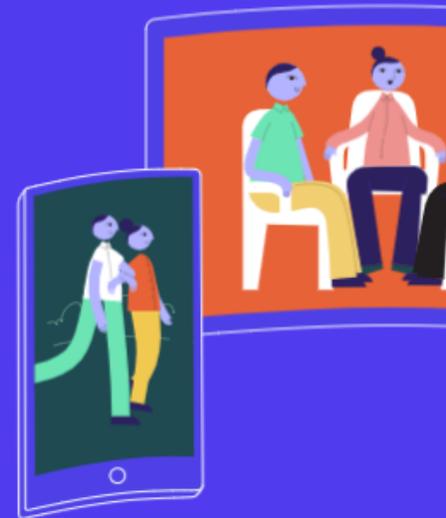
Developed by Message
Lab

SeriousIllnessMessaging.org

Evidence-Based Messaging for Serious Illness Care

If you're a health care professional involved in public outreach, you know that talking to the general public requires a different mindset than talking to a patient. This toolkit is designed to boost your effectiveness in capturing public interest without reinforcing misconceptions.

[How to Use This Toolkit](#)



Get Palliative Care

CAPC's informational
website for patients and
families

GetPalliativeCare.org



[Access the P](#)

[Handout for P
and Families](#)

Are you or a loved one living with a serious illness? Palliative Care can help. Palliative care is specialized medical care focused on relieving the symptoms and stress of a serious illness. It is appropriate at any age and at any stage, and you can have it along with curative treatment. The goal is to improve your quality of life.

Questions & Answers

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