Successful Strategies for Public Messaging and Serious Illness Care

Speakers:

- Marian Grant, DNP, ACNP-BC, ACHPN, FPCN, RN, Senior Regulatory Advisor, C-TAC
- Tony Back, MD, Co-founder, VitalTalk; Co-director, University of Washington Center for Excellence in Palliative Care

Successful Strategies for Public Outreach about Serious Illness Care

Anthony Back MD
Marian Grant DNP ACHPN

University of Washington
CTAC, CAPC, NPHI

Objectives

- Review evidence on attitudes and awareness for advance care planning, palliative care care, and hospice
- Discuss serious illness messaging principles
- Show how to use the principles

What's the issue you or your organization face?

Why This Is Needed

Background

- Long history public health campaigns using marketing techniques: smoking cessation, seat belts, drunk driving, etc.
- Goal: Apply those techniques to palliative care, hospice, and advance care planning
- ***Is*** about introducing these services to the public (public education or outreach)
- ***Not*** about clinical communication with patients
- Public means general people, potential patients, but not necessarily patients or family caregivers
- Messaging is term for this kind of marketing

Aligned messaging could improve public engagement

2 grants 2019-2022, 2022-2025

The John A. Hartford Foundation & Cambia Health Foundation

AAHPM, CAPC, NHPCO, NCHPC, C-TAC, Conversation Project, Respecting Choices, Ariadne Lab Serious Illness Conversation project, Vitaltalk, POLST, AMDA

Project team

- PI- Anthony Back MD,
  University of Washington
- Marian Grant DNP, RN,
  content and marketing consultant
- Patrick McCabe,
  McCabe Messaging Partners

Research shows 3 profiles of public awareness

2011-2020 published studies of consumers

Awareness/attitudes

- Advance care planning (ACP)
- Palliative care (PC)
- Hospice

Findings

- ACP awareness high, participation low
- PC awareness low and misconceptions that it is for end of life
- Hospice awareness high, but concerns about quality & hastening death
- Links to articles on toolkit

MASSACHUSETTS ADVANCE CARE PLANNING CONSUMER SEGMENTS

Worried Action Takers 10%

Younger, diverse, most educated. Nearly half identified as having a disability.

Highest trust and regard for the health care system. ~80% have been a caregiver for an incapacitated loved one.

Self-Assured Action Takers 24%

Oldest by far; most likely to be white and least likely to be low-income.

Confident about managing their health and navigating the health care system with fewer worries about a future serious illness.

Disengaged Worriers 34%

Youngest, most diverse, lowest education and income; poorest health and health care navigation and management skills.

Seen loved one's wishes not honored. Many worries about their health and future serious illness.

Confident Independents 18%

Older (mostly 45+), average education and racial composition. Fewer experiences with dying loved ones. Confident about managing their health and navigating the health care system with fewer worries about a future serious illness.

Self-Reliant Skeptics 14%

Middle-aged, lower income and education.

Lowest trust of doctors and regard for the health care system. Poorer health care self-management and navigation skills.

Palliative care public awareness

- 2021 scoping review
- Public awareness low, 70%+ could not even rate for favorability
- Small proportion who felt familiar had mostly inaccurate perceptions
- 59% of those familiar thought was same as hospice or end-of-life care
- When participants saw CAPC definition 95% rated favorably

2019 CAPC tested language

- Appealing definition
  - -Specialized medical care for people with serious illness.
  - -Goal to improve quality of life for both person and family.
  - -Provided by team of doctors, nurses, and other specialists who work with patient's other providers to provide extra layer of support.
  - -Appropriate at any age and at any stage in a serious illness
  - -Can be provided together with curative treatment.
- But definition not enough
- “Serious” not “~~life-limiting~~”, “~~advanced~~” or “~~terminal~~” illness

Low beneficiary engagement a factor in past palliative care research projects

- CMMI Palliative care projects per 2022 Palliative Project Evaluation
- Factor in recently canceled Medicare Advantage VBID palliative care and hospice program
- Cancelled PCORI palliative care study

What does the public say about the experience of palliative care?

Understanding and Reframing Palliative Care

In partnership with:

Recruitment Overview

Interviews with 16 Caregivers and Patients on Palliative Care

Conducted online, across the nation during October of 2022

N = 8 Caregivers

6 Females / 2 Males

(people who serve as an involved decision maker for someone diagnosed with serious illness)

N = 8 Patients

4 Females / 4 Males

(people diagnosed with serious illness currently receiving palliative care)

Included Conditions:

Heart Disease: 7
Severe Diabetes: 6
COPD: 2
Cancer (Excluding Minor Skin Cancer): 6
Kidney Disease: 3
Liver Disease: 2

**Some participants had multiple diagnoses*

Ethnicity Breakdown:

African American / Black: 5
White / Causcasian: 6
Asian: 2
Middle Eastern / North African: 1
Hispanic / Latino: 2
Native American / Indigenous: 3

**Some participants identified as multiple races*

The ZMET Methodology

Unlock

Unlike a focus group, a ZMET interview frees people to open up about deeply personal feelings that they might otherwise be reluctant to discuss, and to discover unconscious ways of thinking that they might not have been aware of.

Explore

We ask participants to bring in images to the discussion that represent their thoughts and feelings on a given topic. These images serve as a jumping off point for a consumer-led conversation that will help us uncover the deeper emotional meanings around the topic.

Illuminate

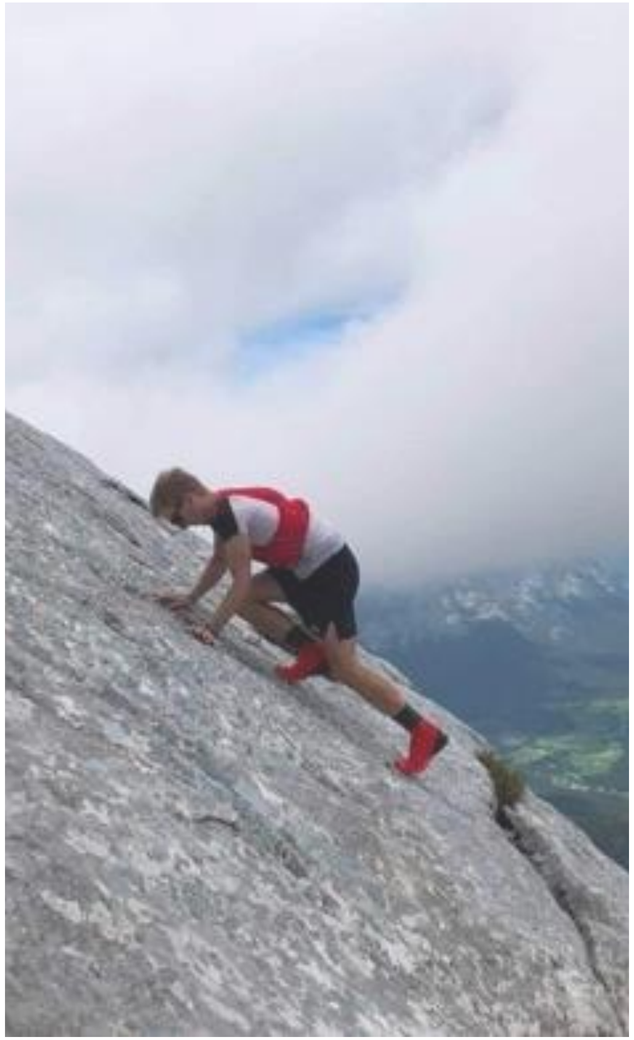
Our analysis explores the imagery that participants bring in as well as the language they use to uncover their deep mental orientations. This, along with our strategic recommendations, provides guidance and inspiration for clients and agencies.

The ZMET Question

“Please choose 4-5 images about why you choose an individualized care approach for your life / the person you care for”

Palliative Care is…

Validation



Agency

Guidance

Regeneration

What I’m Going Through:	I Feel My Needs Are Met When Palliative Care:
I’m ashamed of being ill and feeling weak I feel devastated and alone	Offers **VALIDATION** of what I’m experiencing and how I’m feeling
I don’t feel like I have a say in my care Only I can define my quality of life	Provides **AGENCY** to my unique needs and let’s me be involved in the decisions that affect me
I’m out of options, stuck in this situation I’m lost and uncertain of what lies ahead	Gives me **GUIDANCE** when I need it most, by providing me a network of resources
My illness has stolen my identity and what my life used to be I have to learn to be somebody different	Creates the conditions for **REGENERATION** of my sense of self worth and redefinition of who I am

Image Trend: Palliative Care Helps Me Feel Uplifted Again

How I Feel: VALIDATED
Deep Metaphor: Connection

Offers VALIDATION of what I’m experiencing and how I’m feeling

“Being forgotten about when you're fighting a life threatening disease can be **very degrading**.

“I got to the point where my nurses saw me or my name & they knew me. **It was great to be known and treated with familiarity.**

“I found the center where I was able to develop relationships and not feel like an impersonal process, or part of a machine. **Working with the people, you become a partner. I was partnered with the people there.**”

\-
Ron, Patient

Provides AGENCY to my unique needs and let’s me be involved in the decisions that affect me

How I Feel: INVOLVED
Deep Metaphor: Control

“When we're presented with options, we look at each other after we have the pros and cons and a full explanation of what is being offered.

“The doctor will let us know what he thinks as well, and **we're together to make that decision.**

“**It's important for patients to have a seat at the table**, to make decisions about their health care, and to not allow someone else to do it for them”

-

Phyllis, Caregiver

How I Feel: REASSURED
Deep Metaphor: Resource

Gives me GUIDANCE when I need it most, by providing me a network of resources

“[It’s like] many people that are singing. **They're singing into my care, like a choir** with all the different voices. You have solos here and there, like the oncologist or oncology team singing and doing their thing, and the dermatologist coming in and singing their part.

The different specialists come in when I need them.

“The full choir is **the background support, musical support.** Then the the soloist is the person spotlighted or standing standing out from within the spotlight doing their part at that moment.”

-
Ron, Patient

How I Feel: UPLIFTED
Deep Metaphor: Transformation

Creates the conditions for REGENERATION of my sense of self worth and redefinition of who I am

"When you have somebody that is dealing with an issue constantly, in this case dementia and lack of mobility, I think of palliative care as a way to help them have **as rich of a life as they can within those limitations.**

"If they can go to sleep easier because their needs are being taken care of, that's what I think of [palliative care] as."

-

Rick, Caregiver

Potential Reframing: Illness Takes and Palliative Care Gives

Illness is a thief:	**Palliative Care is a confidant:**
It came into my life uninvited	I choose to bring it into my life
It took a lot from me both physically and mentally	It helps me recuperate both physically and mentally
It left me in a place of devastation and confusion	It puts me in a place of stability and clarity
I am angry at my illness for what it has done to me	I am motivated by my care to press forward in the face of illness

Understanding the Give and Take of Palliative Care

Illness takes away my:	Palliative Care gives me:
Sense of Self Worth	Validation
Autonomy	Agency
Clarity	Guidance
Identity	Conditions for Regeneration

Examples of leveraging metaphors to improve communication

Weaker Examples		Stronger Examples
We know what you are going through	Validation →	We want to hear your story and understand you better
We provide quality care and keep you informed about your care	Agency →	You're the leader of your care team
It's hard to get through illness on your own	Guidance →	Together, we can create a plan to move forward
You can live a comfortable life	Conditions for Regeneration →	You can reclaim ownership of your life

What about other providers?

How serious illness specialists see palliative care

ZMET® QUESTION/REQUEST

Think about ALL your experiences with palliative care… what is it like for you to consider palliative care for one of your patients… what does it mean for you when you consider palliative care?

What have the situations and discussions that you have had with patients and other clinicians meant to you?

What ideas are coming to you?

Please select 4 or 5 images that represent your thoughts and feelings about your experiences with palliative care

WE ASKED CLINICIANS ABOUT THEIR EXPERIENCES WITH PALLIATIVE CARE. WHAT DO YOU SEE?

In practice, specialists follow evidence-based algorithms

but Palliative Care isn't on those algorithms and feels outside of their evidence-based world

I HAVE TO TELL PATIENTS THE RIGHT INFORMATION AND PATH

“There are **so many different routes and steps,** and it’s confusing to navigate. Some stairs lead to other staircases but some are dead-ends.

“When patients try to navigate the healthcare system, it can feel like that. I try to **give people information on where to go next** and **guide them.”**

- Sara, PA

“It makes **me feel like I provided enough information**, you are aware and we've **answered all the questions.**”

- Alison, PA

“My job is to be informational, and making sure I'm giving the patients the right options.”

- Prashant, MD

MY “RULES” ARE BASED ON OBJECTIVE DATA

“**Data collection** and monitoring”

“**Cut and dry**”

“**Systematically** run through the **list** of treatments”

“Looking for the **protocol** around it”

“**Black and white**”

“**Objective** data, we’ve got to fix this”

“Historical, **data-based**, end stage **markers**”

“We use **guidelines and measurements**, a lot of **quantitative** data”

NOT ALLOWING MYSELF TO MAKE MISTAKES

“It's been hammered into us, right? That **if you fail, somehow it is your fault.** So you have to be at the top of the game, and **you have to be perfect.”**

- Ely, MD

“**The scary part is** patients not believing you or **being wrong**. I think what scares providers more than anything else is making the wrong recommendation to the patient.
- Taylor, NP

“To me, it's working hard, and making sure I'm **following all the guidelines**, making sure I'm addressing all the patient's needs, answering all their questions, and just **making sure I'm not making any mistakes**.”

- Prashant, MD

DEPENDING ON ALGORITHMS TO GIVE PATIENTS THE BEST CARE

“In cardiology, **we use algorithmic guidelines,** we use measurements, we use a lot of **quantitative data, to make judgments** about a patient's condition.

“If a patient asks you a question about whether or not they should take aspirin, you've got a **scripted response** in your head at all times to give them. **Easy peasy,** you do it every day.**”**

- *Taylor, NP*

PALLIATIVE CARE DOESN'T FOLLOW OUR ALGORITHMS

I don't know of any significant **concrete guidelines** in palliative care, except for code status. **There's no algorithmic guidelines, like we have in cardiology.** When the **plan changes, it throws us off**."

- Taylor, NP

"Palliative care would be **a very abstract picture**. More like **a grey scale** with lots of shapes and swirls that trace back and are swirling to other areas. It's **hard to follow it**."

- Sara, PA

THERE IS NO OBJECTIVELY RIGHT DECISION WITH PALLIATIVE CARE

“These conversations are much more **like a therapy session**, versus what we consider to be a **typical diagnosis and treatment route** that you’d associate with medicine, where we consider there to be a right and wrong answer. **In Palliative Care, there isn't a right and wrong answer**.

“It forces you to now be in somebody else's shoes and consider **what can we offer with this new context.**

“So it absolutely **shifts the way you look at things from the paradigm model** we use when we look at things medically. It switches to more human-centric. You **can’t really train someone** for that.”

- David, PA

INVITING PC IS ADDING UNCERTAINTY UNLESS I'M AT THE END

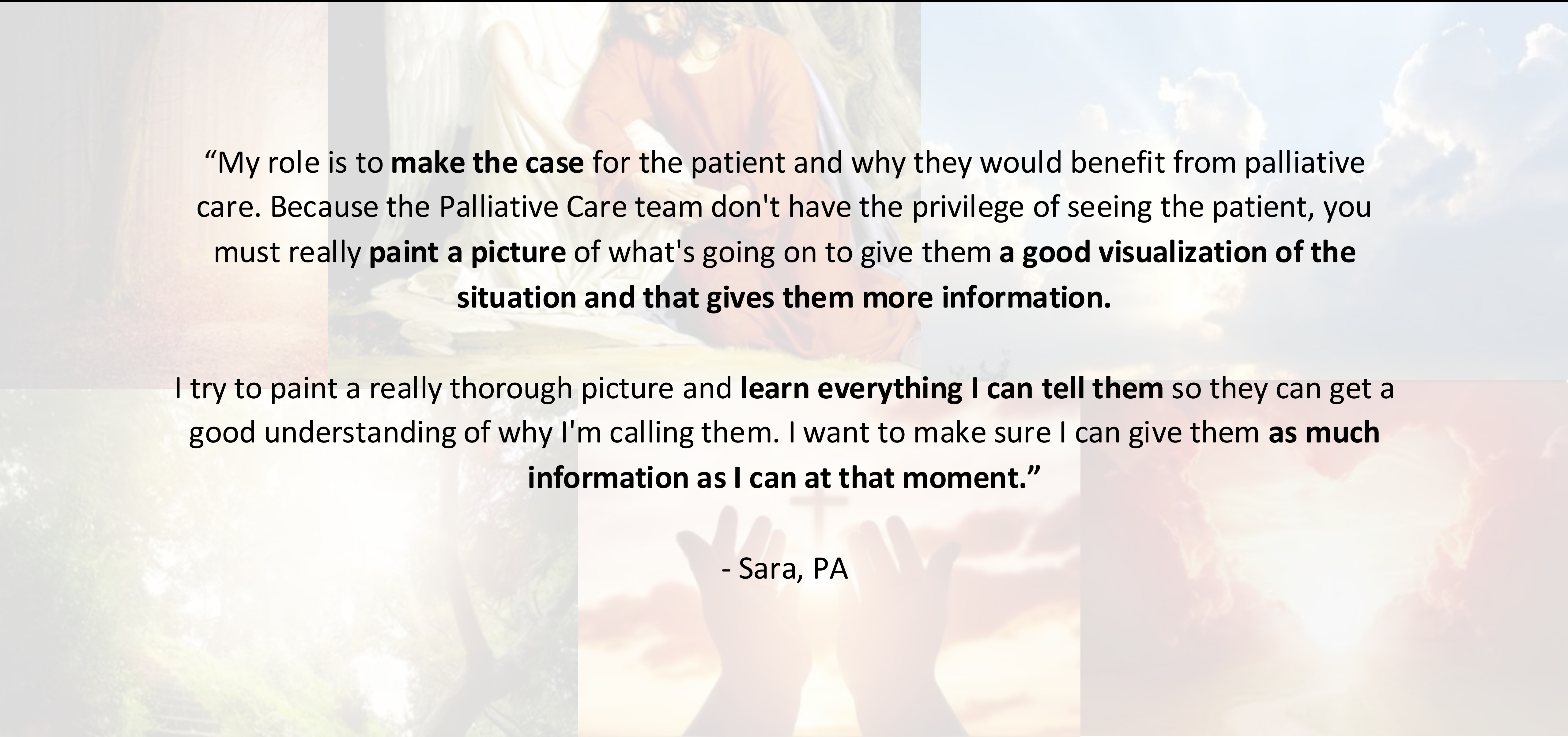
“Palliative care is complicated. As an area of specialty it's brand new. So it's interesting to **try to figure out where it fits in** for a lot of individuals, a lot of families, **a lot of HCPs really aren't sure where palliative care fits in.**”

- *Apollo, MD*

“After I've run all the tests, and used all the tools that I have in my toolbox, that’s when I will refer Palliative Care. It's like **an add on or an extra app outside of my toolbox** or expertise.”

- *Sara, PA*

THUS I WAIT UNTIL THE VERY END BEFORE CONSIDERING PALLIATIVE CARE



“My role is to **make the case** for the patient and why they would benefit from palliative care. Because the Palliative Care team don't have the privilege of seeing the patient, you must really **paint a picture** of what's going on to give them **a good visualization of the situation and that gives them more information.**

I try to paint a really thorough picture and **learn everything I can tell them** so they can get a good understanding of why I'm calling them. I want to make sure I can give them **as much information as I can at that moment.”**

- Sara, PA

DON’T SUGGEST A TAKEOVER

1. CUE INTEGRATION INTO THEIR SYSTEM

AVOID		TRY
‘Handoff’ to PC	→	We can combine our strengths
‘Referring’ to PC	→	We add additional resources
Separating from their system	→	Working alongside

DON’T ASK THEM TO RELY ON JUDGMENT CALLS

2. IDENTIFY AN ‘OBJECTIVE’ INDICATOR

AVOID		TRY
‘consider’ PC	→	A second line regimen is the time to consult PC
‘poorly controlled’ symptoms	→	A pain score of 8 on first line opioids

DON’T GUILT TRIP THEM WITH PC MANTRAS

3. CONNECT WITH THEIR MINDSET

AVOID	TRY
‘The patient is ready’ for PC	In this situation, 70% of oncologists like you consult us.
‘Have you elicited their goals?’	80% of our consults are from Cardiologists in this same situation

DON'T TRIGGER UNCERTAINTY OR ASK THEM FOR A LEAP OF FAITH

AVOID

‘patient-centered’

‘we’ll make it easier for you’

4. SHOW HOW PC FITS INTO THEIR SYSTEM

TRY

We can build on what you’ve accomplished

We can align our efforts

Tested Messaging Principles

Messaging principles are evidence-based ways of talking to the public

- We can’t use ourselves as the target audience.
- Our nuanced views of palliative care aren’t being heard.
- But we don’t have to all share the same phrases. You need to talk about the work you or your organization does.
- To do that, we can use communication strategies that have worked in public campaigns and trusted brands.
- This approach could work for your outreach.

2019 Consumer & clinician focus groups

- Denver & Baltimore
- 8-9 per group; semi-structured moderation
- Demographics
  - Participants age 70+
  - Participants age 50-70
  - More than a third of the participants were ethnically diverse
  - All had medical coverage of some kind
- Did again in 2020 after Covid with little change

Public Education / Messaging Principles

1 **Talk up the benefits**

These services and care improve peoples’ lives.

2 **Present choices for every step**

At every stage of an illness, you have choices.

3 **Use stories**

The stories that resonate are positive and aspirational.

4 **Invite dialogue—and not just once**

The call to action is to talk with someone.

5 **Invoke a new team**

Patients, families, clinicians, & community all have a role.

Focus groups reactions

Talk up the benefits

“It gives you a handle on the illness and it kind of broadens your mind. It takes some of the pain away, some of the anxiety away.”

Present choices for every step

“It gives you a sense of control. It’s what you want, not what they want.

Use stories

“You can relate to something like this because the alternative is to explain how 72% of the people do this and 32% of them do that. I’d rather have anecdotes about people.”

Invite dialogue

“The important thing is getting the conversation going, and this is not threatening. It’s reassuring to me.”

Invoke a new team

Participants liked the inclusivity of framing the conversation around “we” and naming all the players relevant to the conversation (patients, loved ones, care team).

Palliative care heart failure story

Laura, 72, enjoyed her retirement until she noticed she was having trouble keeping up with her friends on their walks.

She went to her primary care doctor, and then a heart specialist, who found out that she had had a silent heart attack.

A few weeks later, Laura had another heart attack and ended up in the hospital with heart failure.

A nurse, Nicole, came to see Laura. Nicole explained that she was on the palliative care team, which meant focusing on helping people live well, even with a serious illness.

Nicole asked Laura what was most important to her about her care, and then arranged support that Laura didn't know existed. That included giving her medication for pain, helping her with how to talk about her illness with her grandchildren, and a social worker to provide support to Laura's husband.

A few weeks after starting palliative care, Laura is starting to feel more normal again and back to enjoying some of the activities she used to do.

Consumers don’t get our terminology

Terms widely used in serious illness care fraught with misconceptions:

- Nearly all who had heard of palliative care thought was for end of life
- Most were confused by idea that they should express preferences or set goals

Participant comfort with conversations seemed to correlate with positive past experience.

Most prefer conversations be initiated by a long- term provider.

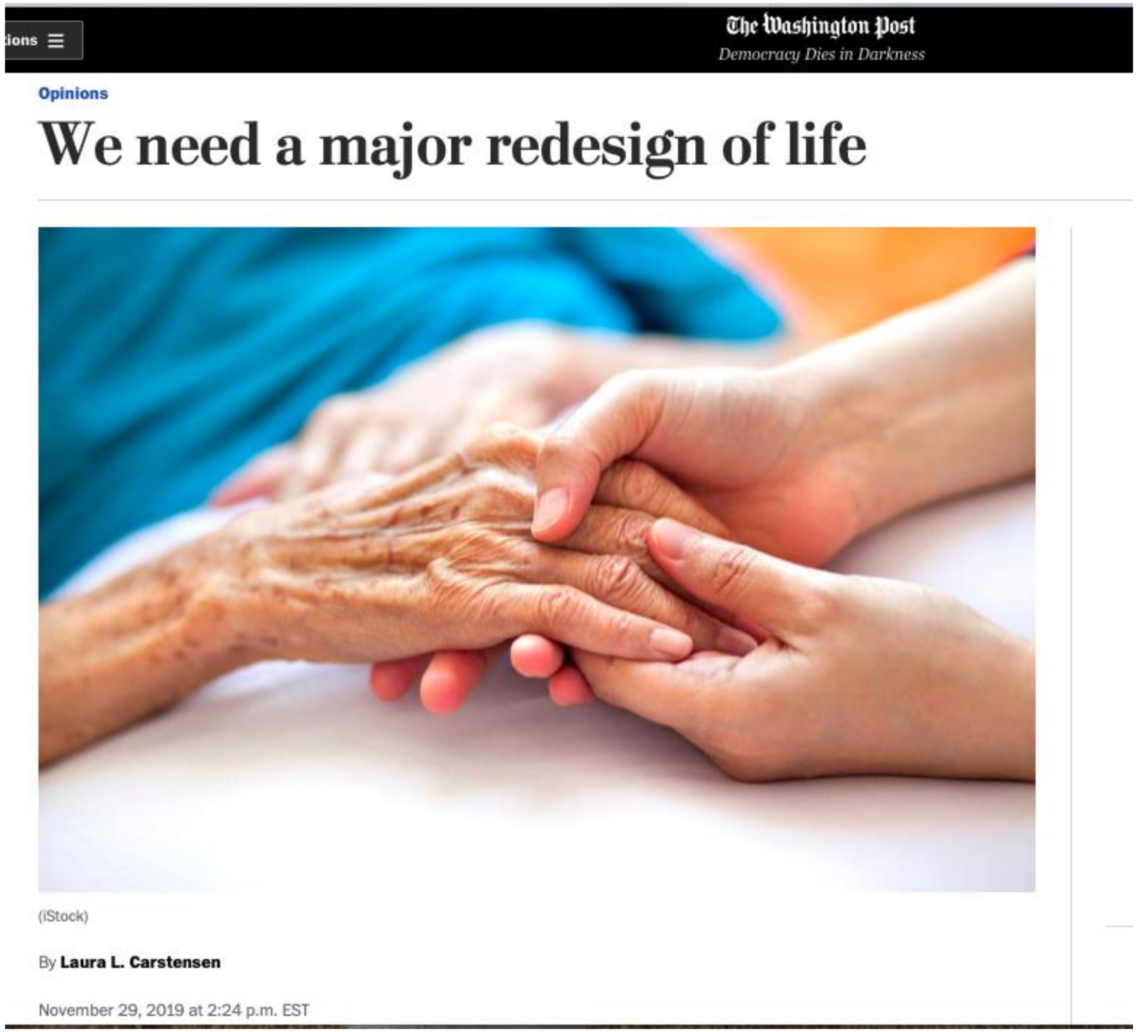
Visuals

- Should be positive and aspirational
- Should reinforce the benefits of serious illness care
- Instead of hands, show what living well looks like
- The goal is motivation, not veracity

But we’ve trained CMS and the media

CENTERS for MEDICARE & MEDICAID SERVICES

Medicare Hospice Benefits



The Washington Post

Democracy Dies in Darkness

Opinions

We need a major redesign of life

(iStock)

By **Laura L. Carstensen**

November 29, 2019 at 2:24 p.m. EST

Using the Serious Illness Messaging Toolkit

Steal our messages!

Download our curated visuals

Learn more about effective outreach

Share with your communications professionals

Quick Guides

Palliative Care

What you'll learn

- How best to introduce palliative care to the public.
- Why *not* to message palliative care as end-of-life.
- How to illustrate what palliative care does

What to do and not do when talking to the public about palliative care

Here are some examples we've curated, and why they work.

Instead Of..	Do This..
Introducing palliative care by explaining how it’s not hospice	Show how the extra layer of support palliative care provides can help someone live well with a serious illness.
Before	After
The goals of hospice and palliative care are very similar: to relieve symptoms of a serious illness, provide comfort from pain, and improve	Palliative care helps people with serious illness stay at home rather than having to go to the ER or the hospital. It reduces physical

CMS Talksheet

Palliative Care vs. Hospice Care

Similar but Different

Palliative Care

- Focuses on relief from physical suffering. The patient may be being treated for a disease or may be living with a chronic disease, and may or may not be terminally ill.
- Addresses the patient's physical, mental, social, and spiritual well-being, is appropriate for patients in all disease stages, and accompanies the patient from diagnosis to cure.
- Uses life-prolonging medications.
- Uses a multi-disciplinary approach using highly trained professionals. Is usually offered where the patient first sought treatment.

Hospice Care

- Available to terminally ill Medicaid participants. Each State decides the length of the life expectancy a patient must have to receive hospice care under Medicaid. In some States it is up to 6 months; in other States, up to 12 months. Check with your State Medicaid agency if you have questions.
- Makes the patient comfortable and prepares the patient and the patient's family for the patient's end of life when it is determined treatment for the illness will no longer be pursued.
- Does not use life-prolonging medications.
- Relies on a family caregiver and a visiting

Palliative Care Messages
You Can Steal

You can live well while caring for your heart.

Spend more time at home. But keep the best care.

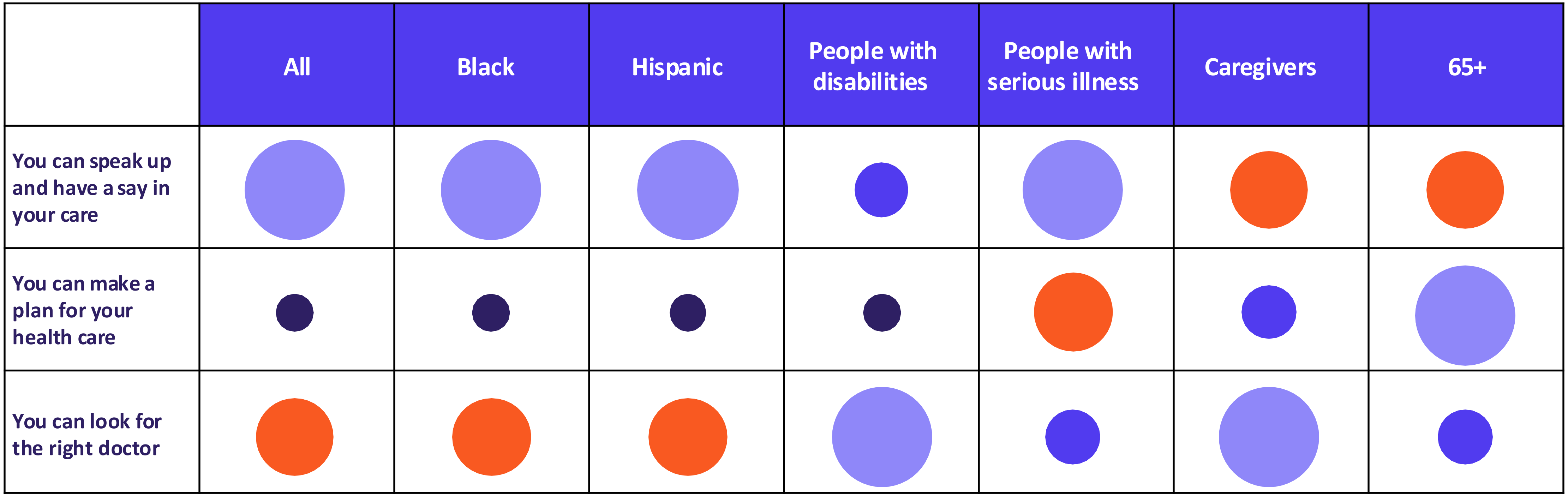
We get your doctors to talk to each other.

When all your doctors tell you something different, we can help.

At every stage of a serious illness, we’re here.

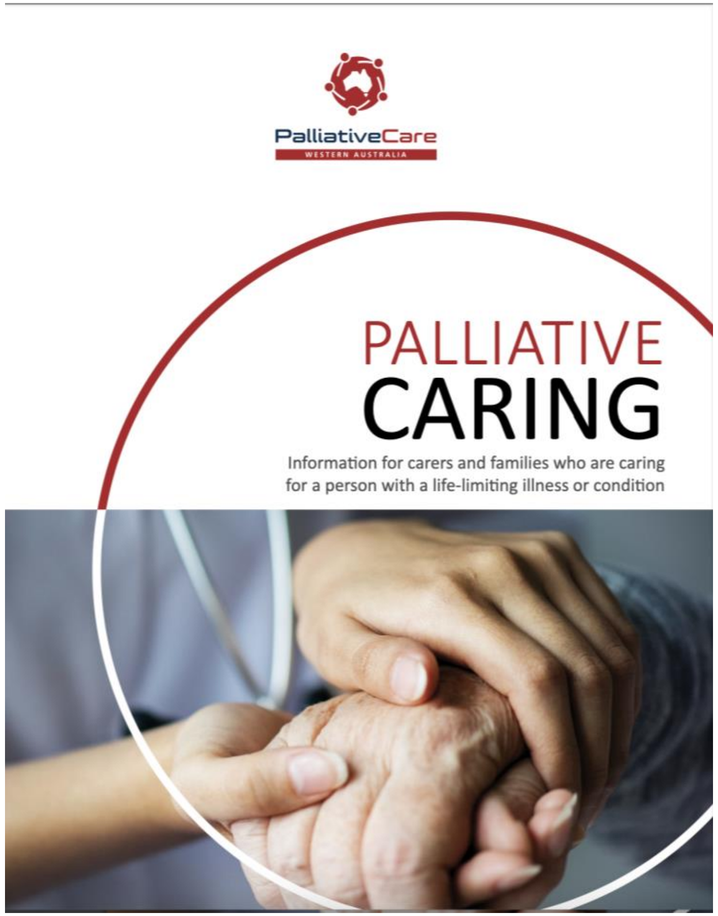
Ask for Palliative Care.

Message impact by diverse communities on a qualitative discussion board



	All	Black	Hispanic	People with disabilities	People with serious illness	Caregivers	65+
You can speak up and have a say in your care	●	●	●	●	●	●	●
You can make a plan for your health care	●	●	●	●	●	●	●
You can look for the right doctor	●	●	●	●	●	●	●

Test your messages & visuals



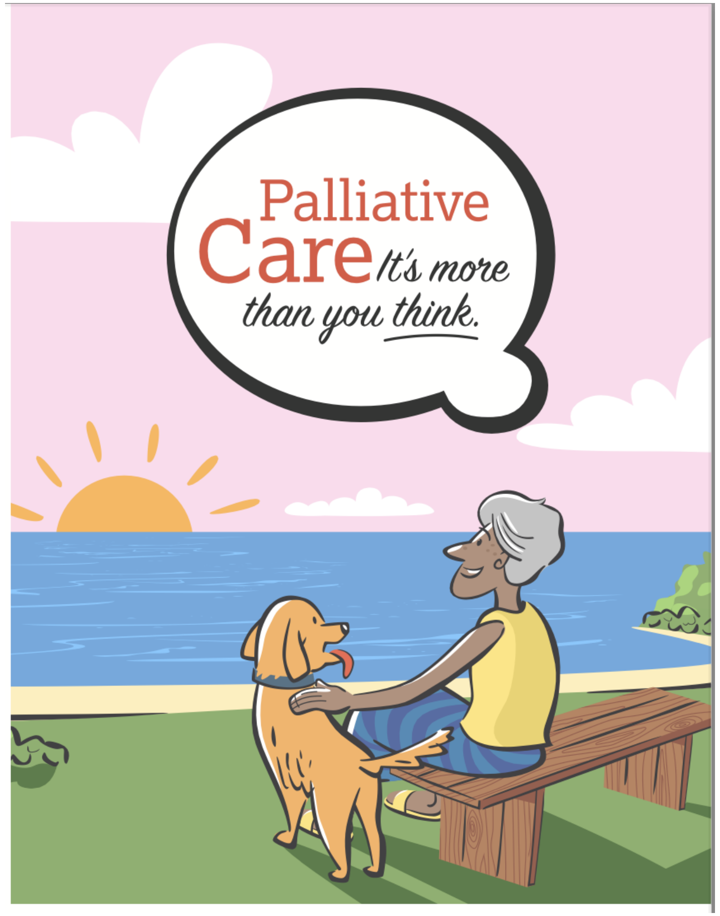
PalliativeCare
WESTERN AUSTRALIA

PALLIATIVE
CARING

Information for carers and families who are caring for a person with a life-limiting illness or condition

"Well... everyone's trying to help...

*mmm... I feel like this is *it*, do I have everything in order?"*



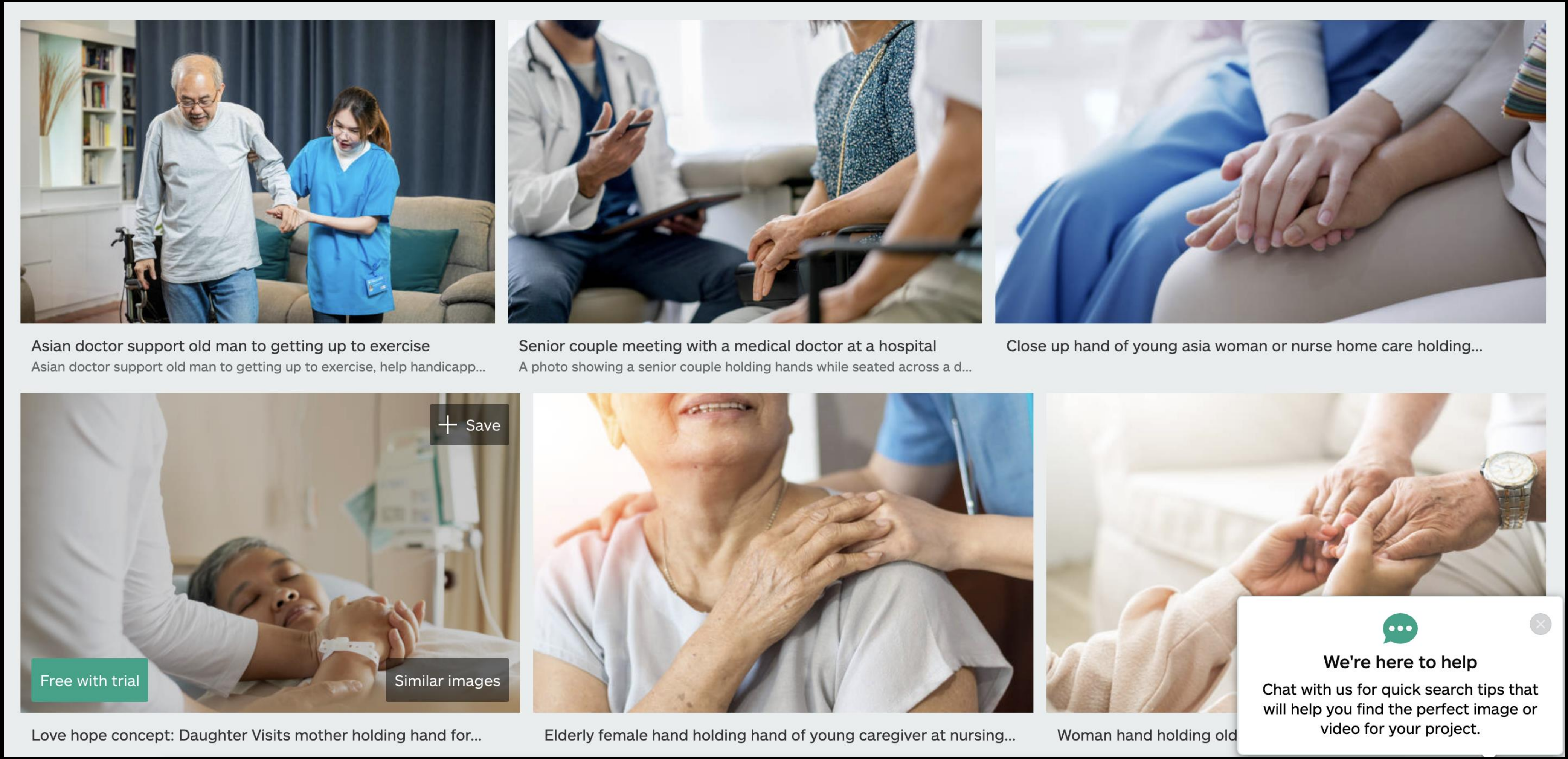
"Well, it looks very friendly.

It's not intimidating because I'm sitting outside with my dog.

Doesn't look like I am on death's doorstep."

How does your existing messaging stack up against these principles?

You cannot depend on image search



Asian doctor support old man to getting up to exercise
Asian doctor support old man to getting up to exercise, help handicapp...

Senior couple meeting with a medical doctor at a hospital
A photo showing a senior couple holding hands while seated across a d...

Close up hand of young asia woman or nurse home care holding...

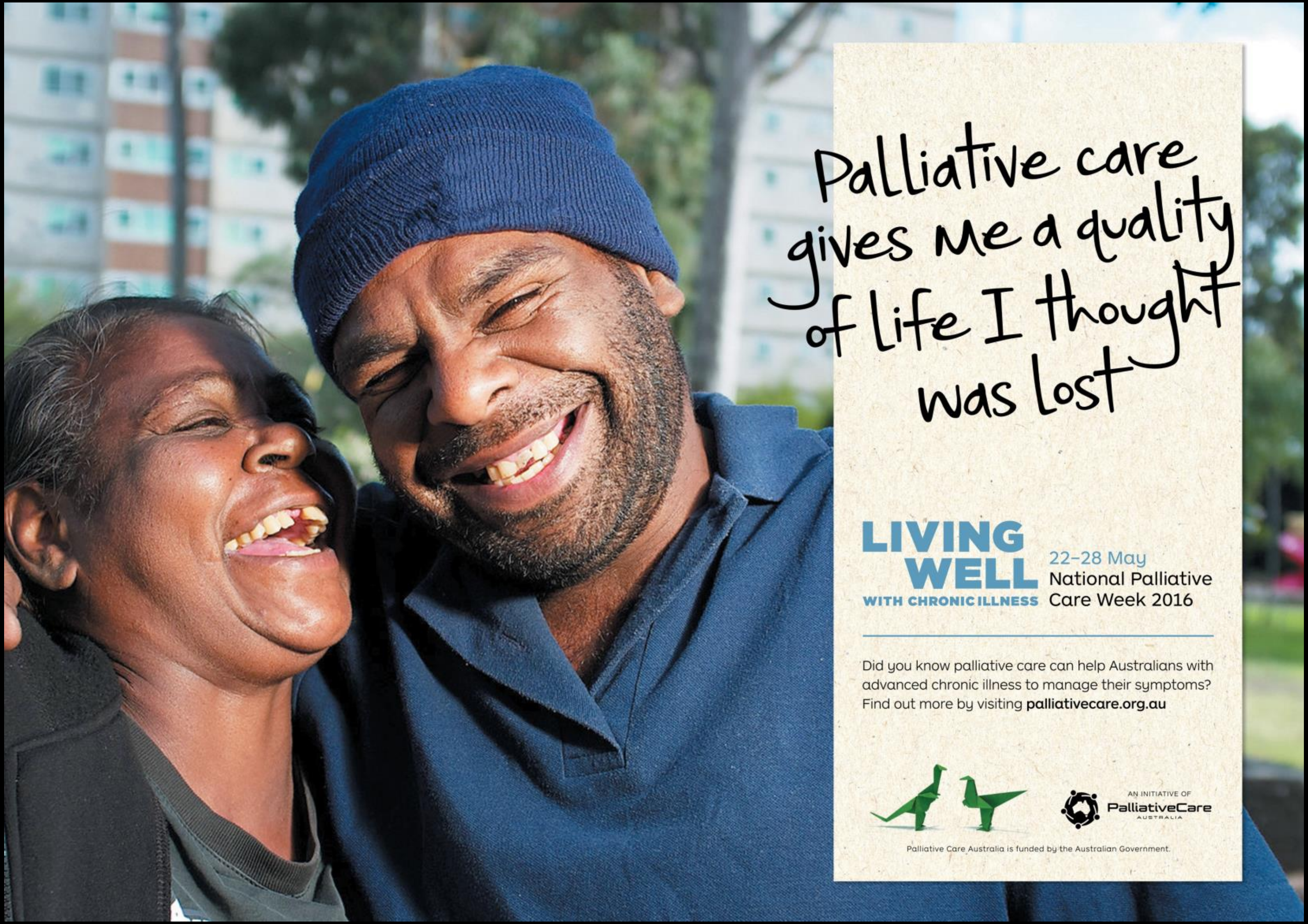
Love hope concept: Daughter Visits mother holding hand for...

Elderly female hand holding hand of young caregiver at nursing...

Woman hand holding old

We're here to help

Chat with us for quick search tips that will help you find the perfect image or video for your project.



Palliative care gives me a quality of life I thought was lost

LIVING WELL
WITH CHRONIC ILLNESS

22–28 May
National Palliative Care Week 2016

Did you know palliative care can help Australians with advanced chronic illness to manage their symptoms? Find out more by visiting **palliativecare.org.au**

AN INITIATIVE OF
PalliativeCare
AUSTRALIA

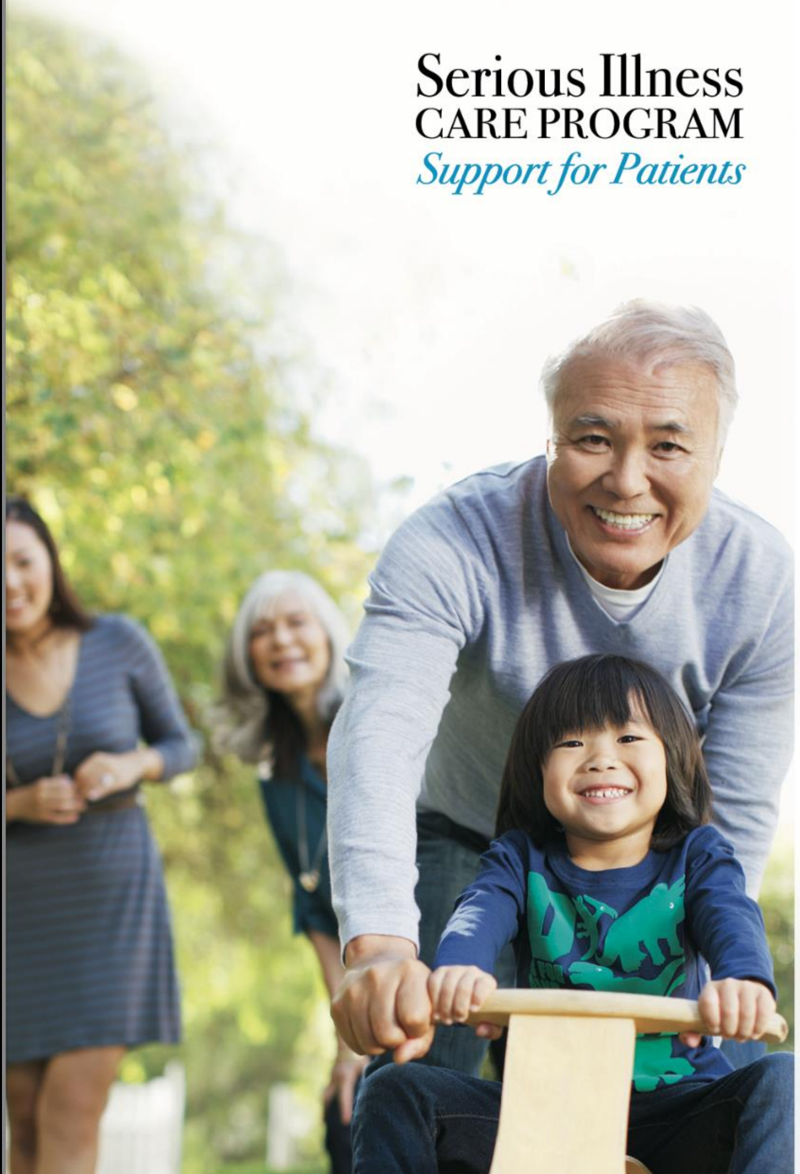
Palliative Care Australia is funded by the Australian Government.

Palliative care for LGBTQ+ people in NSW

MAKE EACH DAY MATTER

Blue Advantage
A Medicare Approved PPO

Serious Illness CARE PROGRAM
Support for Patients



When you have a serious illness, sometimes your only goal is to have a good day. Deciding what matters to you and talking about what a good day looks like is a great start.

How can the Serious Illness Care Program help? By focusing on your needs and providing an extra layer of care. We aim to align your treatment with your health goals and help manage your symptoms and stress.

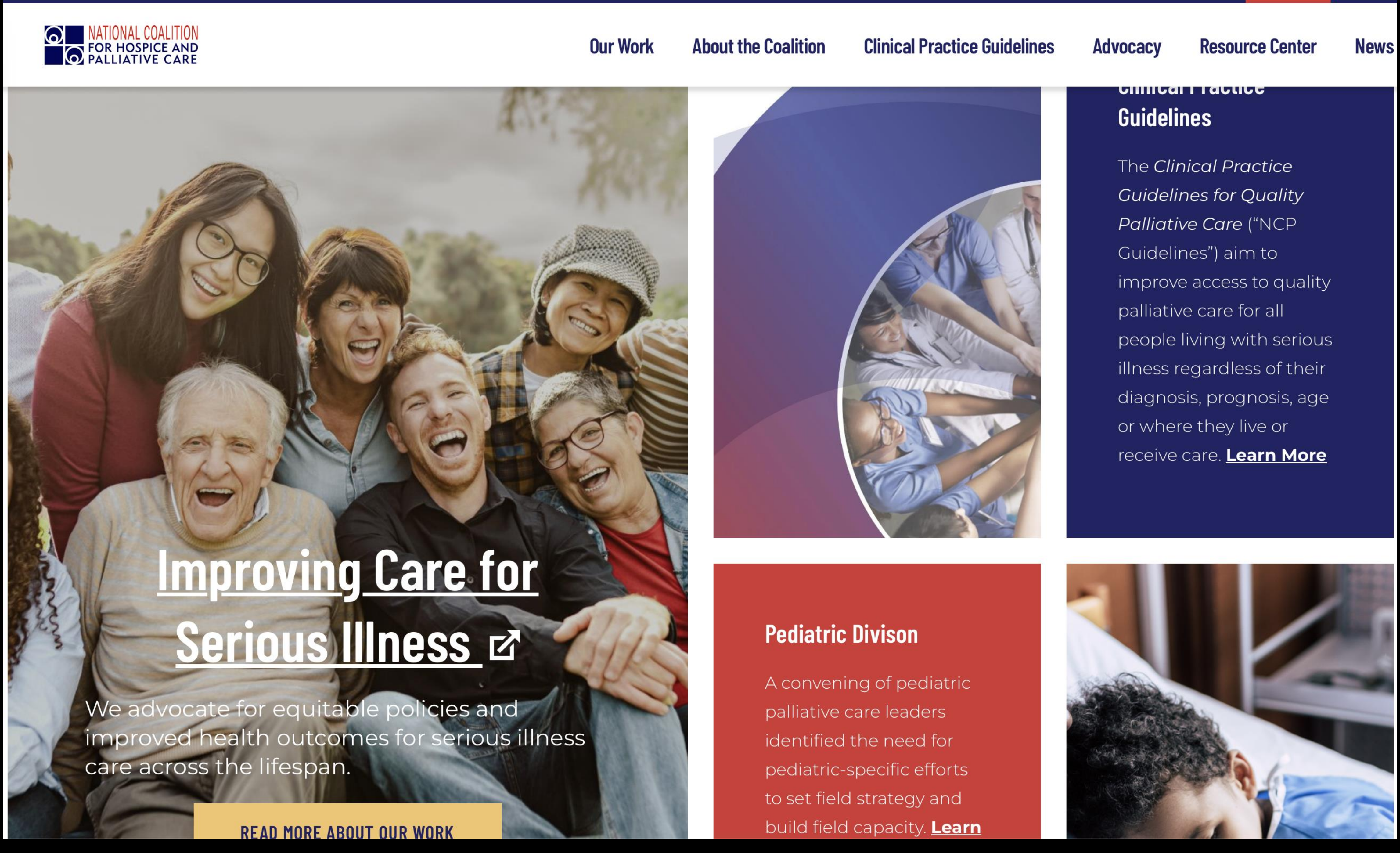
Here's How We Can Help

The Serious Illness Care Program offers extra care and support focused on you. You will have a nurse who calls you to:

- Help with pain and other problems
- Schedule (coordinate) your doctor appointments
- Talk about what matters to you
- Teach you about your condition
- Support you and your caregiver

Is This Program Right For You?

You will benefit from the program if your serious illness affects your daily life. Impacting your daily life might look like:



Improving Care for Serious Illness

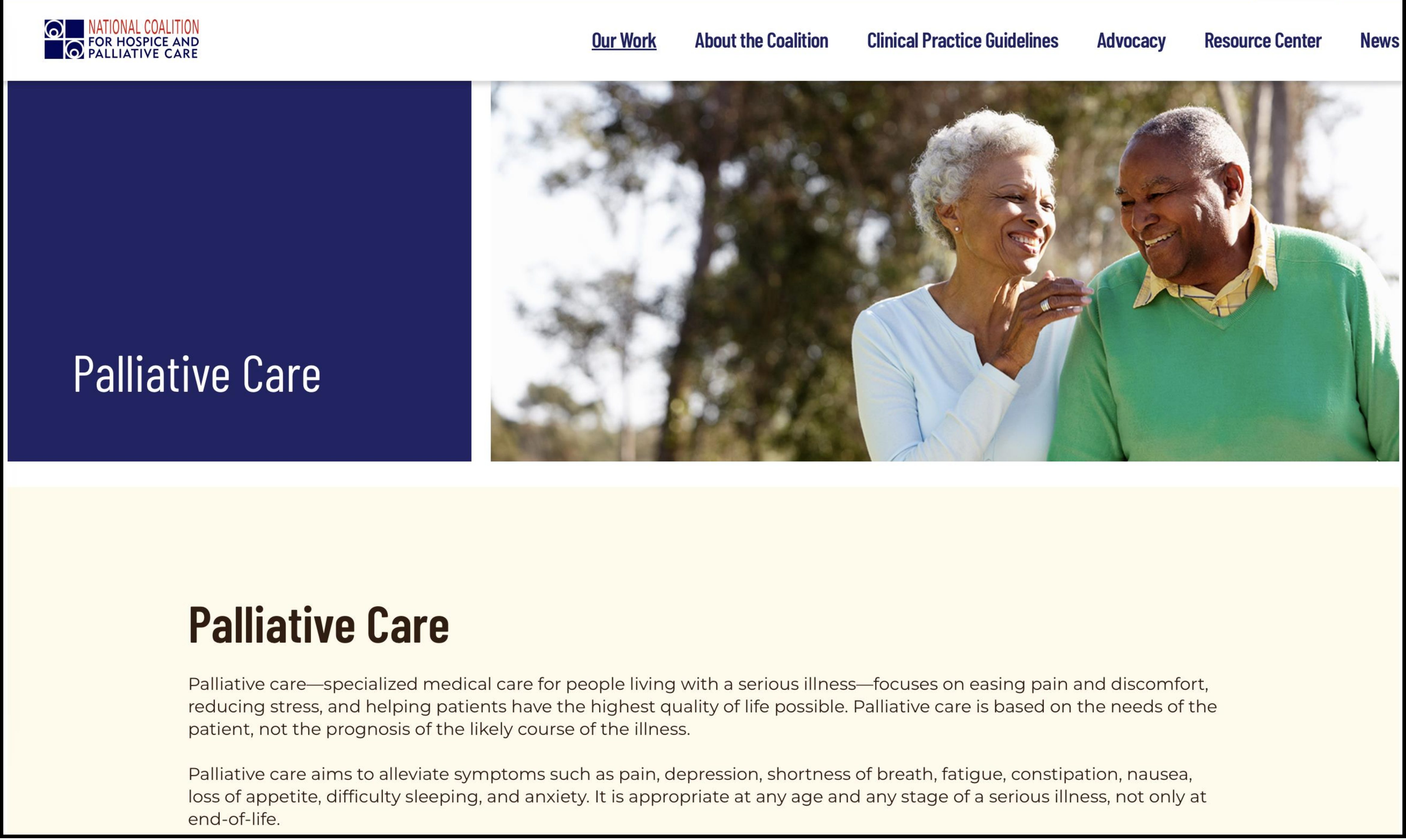
We advocate for equitable policies and improved health outcomes for serious illness care across the lifespan.

Clinical Practice Guidelines

The *Clinical Practice Guidelines for Quality Palliative Care* ("NCP Guidelines") aim to improve access to quality palliative care for all people living with serious illness regardless of their diagnosis, prognosis, age or where they live or receive care. **Learn More**

Pediatric Divison

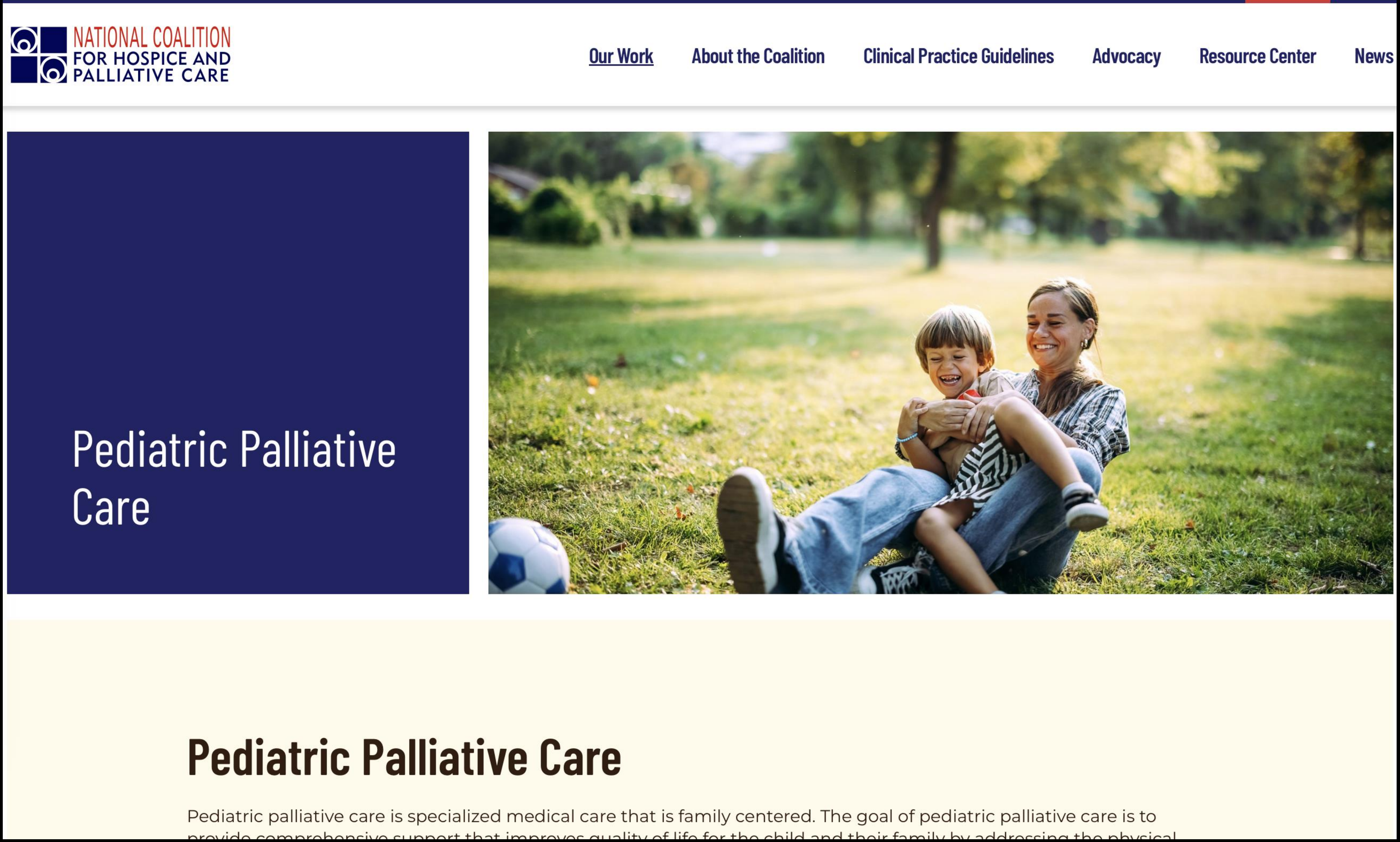
A convening of pediatric palliative care leaders identified the need for pediatric-specific efforts to set field strategy and build field capacity. **Learn**



Palliative Care

Palliative care—specialized medical care for people living with a serious illness—focuses on easing pain and discomfort, reducing stress, and helping patients have the highest quality of life possible. Palliative care is based on the needs of the patient, not the prognosis of the likely course of the illness.

Palliative care aims to alleviate symptoms such as pain, depression, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, and anxiety. It is appropriate at any age and any stage of a serious illness, not only at end-of-life.



NATIONAL COALITION
FOR HOSPICE AND
PALLIATIVE CARE

Pediatric Palliative Care

Pediatric Palliative Care

Pediatric palliative care is specialized medical care that is family centered. The goal of pediatric palliative care is to provide comprehensive support that improves quality of life for the child and their family by addressing the physical

https://Seriousillnessmessaging.org

Anthony Back
tonyback@uw.edu
Marian Grant
consultant@MarianGrant.com