Translating Research into a Toolkit for Public Outreach

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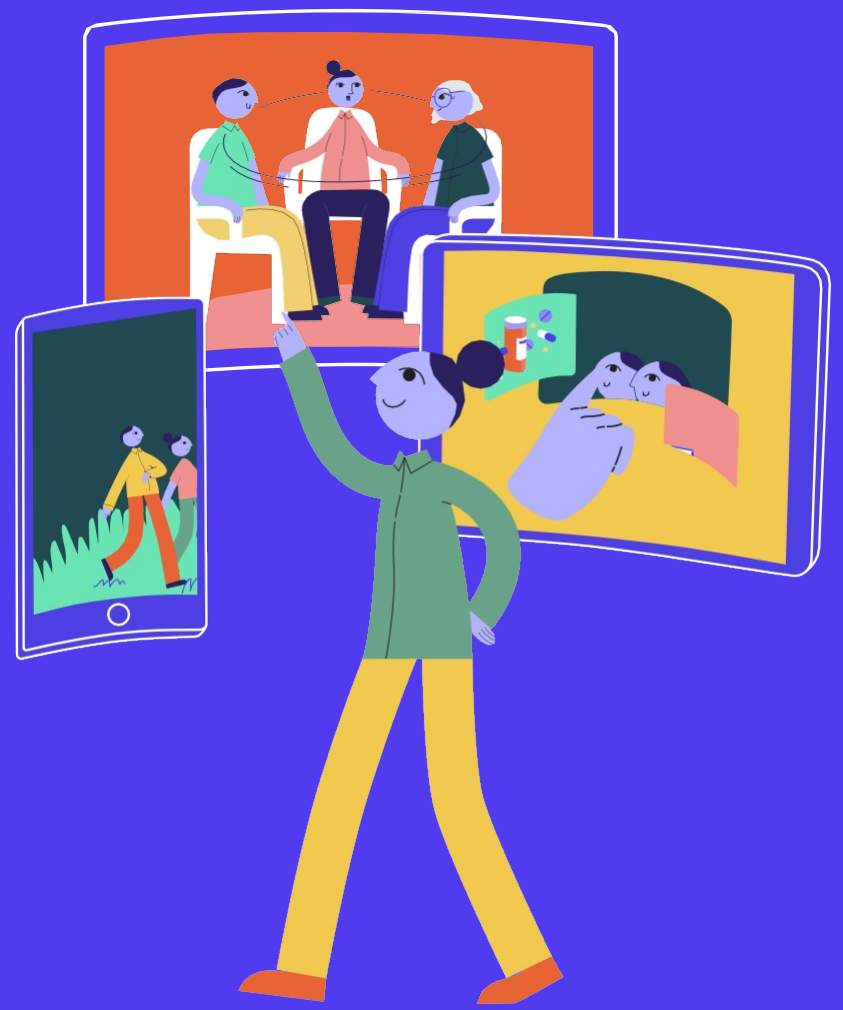
http://seriousillnessmessaging.org

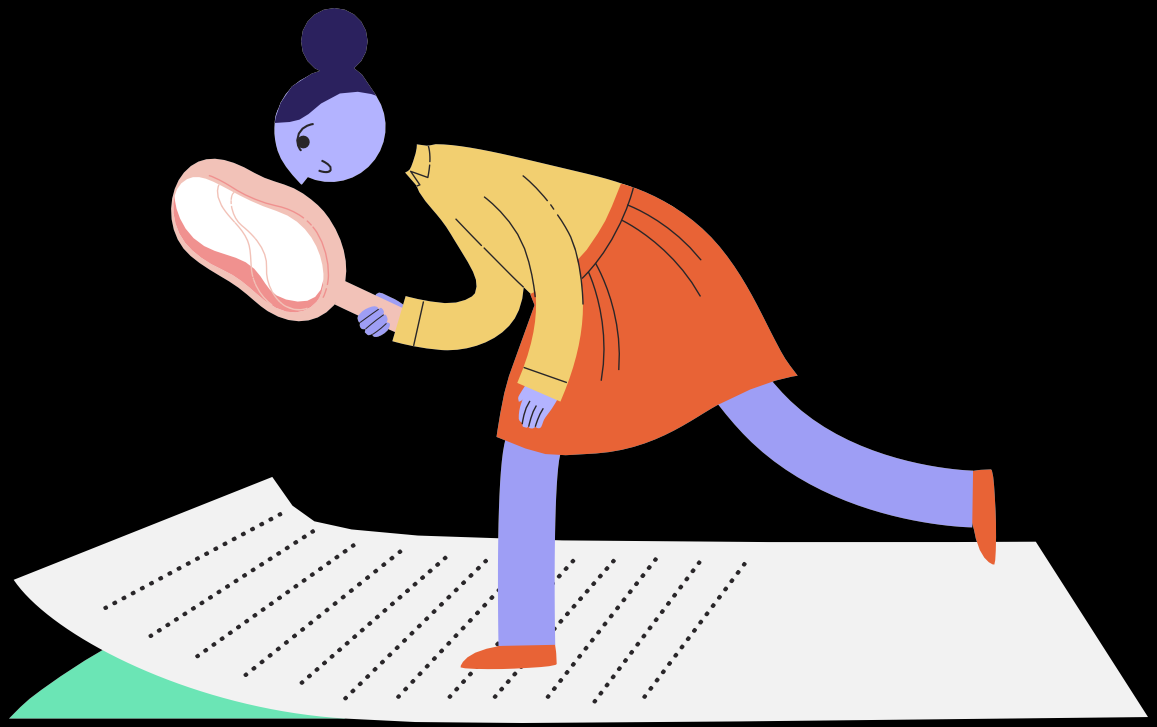


What We'll Cover

New framing for Palliative Care services

New research on patient experience

Using the Serious Illness Messaging Toolkit



A new frame for PC: ‘prevention’

Just approved!

A new Medicaid benefit for Hawaii

Designating palliative care as a ‘preventive’ service

Endorses *early* PC to avoid unnecessary suffering and hospitalization

Palliative Care as a ‘preventive’ service

Hawaii may have opened a path that other states can follow

The Hawaii Community PC benefit approved by Medicaid

Defines palliative care based on needs
Provided along with curative therapy

Care plan aligned with patient & family goals
Interdisciplinary team

Messaging implications:

We should use and test ‘prevention’ as a frame for public outreach

Encourage evidence-based message development to avoid failures of prior PC demonstration projects.

Empirical research in the toolkit

Nationally representative surveys

Oversampling of underserved populations

In-depth focus groups

A stakeholder process with all the professional organizations

Consumers don’t get our terminology

Our focus groups struggled with **misconceptions:**

Nearly all who had heard of palliative care thought it was ***only* for end of life.**

Most found the idea that they should express preferences or set goals was confusing…**counter to their lived experience.**

Our own commentaries continually reinforce our brand as ‘dying’

But patients with a lived experience of palliative care say:

"I felt **validation** for what i was going through."

"I found **agency** to determine what quality of life meant for me."

"I had **guidance** to a new network of resources."

"I regenerated my **self-worth**."

J Palliat Med 26:6, 751-6

We've condensed the research into 5 principles

01 **Talk up the benefits**

These services and care improve peoples' lives.

02 **Present choices for every step**

At every stage of an illness, you have choices.

03 **Use stories**

The stories that resonate are positive and aspirational.

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

The call to action is to talk with someone.

05 **Invoke a new team**

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

Trust in the healthcare system is low

Focus group participants: not a lot of trust in healthcare if they it for a serious illness.

Q: Do you trust the healthcare system to do right by you if you were diagnosed with COVID or another serious illness in the next few months or years?"

A: "No… I mean, I want to say yes."

A: "It's in such flux right now because everything's political and we don't know what type of healthcare system we're going to have from one election to the next."

Using the Serious Illness Messaging Toolkit

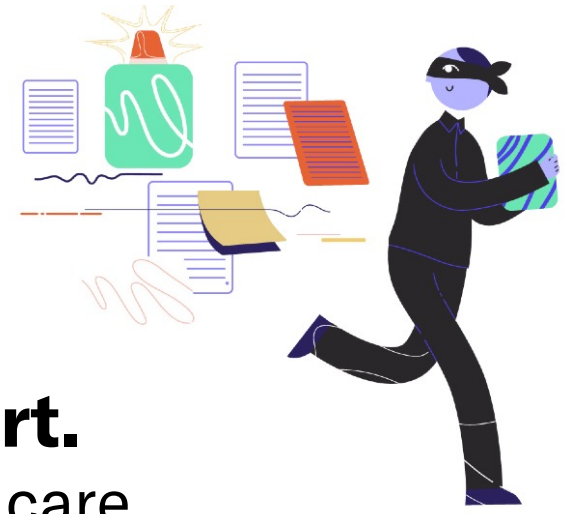
Steal our messages!

Download our curated visuals

Learn more about effective outreach

Share with your communications professionals

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.

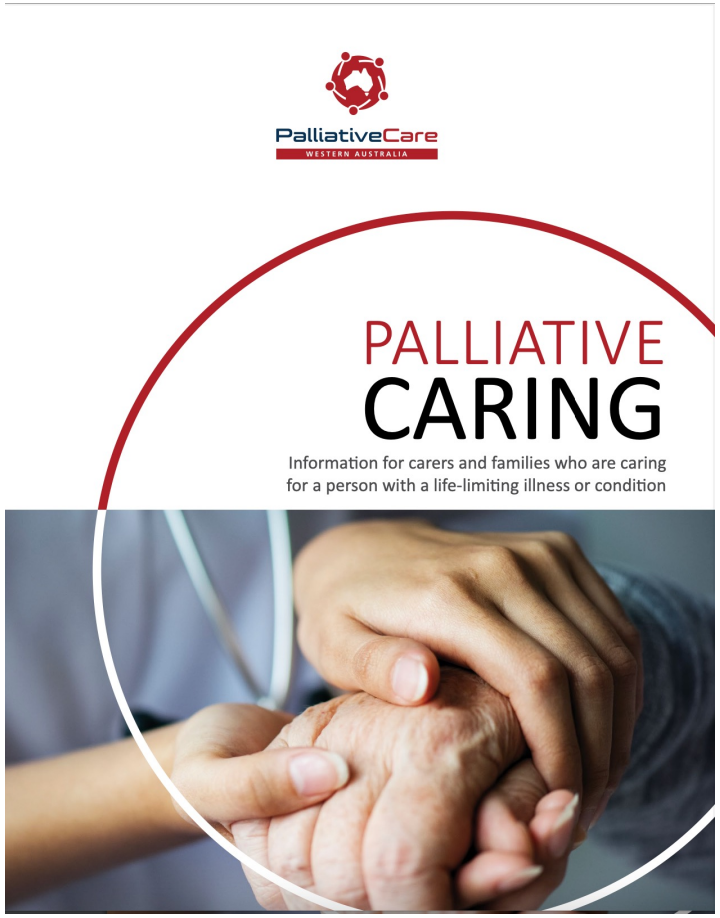
At every stage of a serious illness, we’re here.

Ask for Palliative Care.

Message impact by diverse communities on a qualitative discussion board

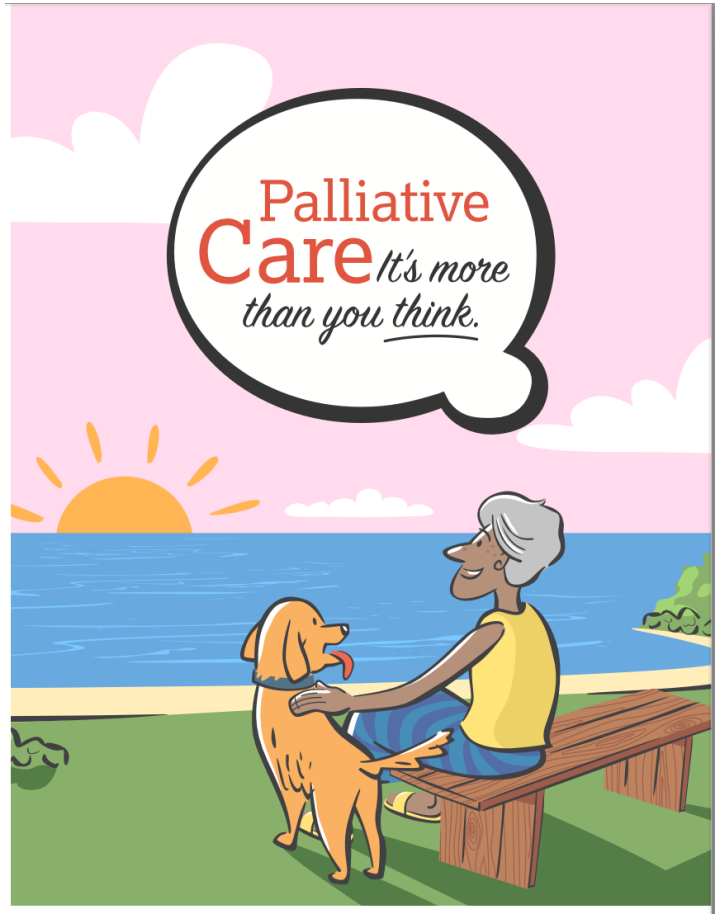
	All	Black	Hispanic	People with disabilities	People with serious illness	Caregivers	65+
You can speak up and have a say in your care							
You can make a plan for your health care							
You can look for the right doctor							

Test your messages & visuals



"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?

Find the toolkit at:
seriousillnessmessaging.org

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