Educating the Public About Palliative Care:

GetPalliativeCare.org



Our Mission

The Center to Advance
Palliative Care
(CAPC) is a national organization dedicated to increasing the availability of quality, equitable health care for people living with a serious illness and their caregivers.



The goal

Educate the public about:

- What palliative care is
- The benefits for patients and families
- How to get it









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Talk Up the Benefits

Rather than telling them what we think they should know about aspects of serious illness care, effective messaging highlights what they care about -- the benefits. The old messaging about avoiding a bad death doesn't work here. For advance care planning, what works is letting people know that they can have a say in their care. For palliative care, it's about an extra layer of support that lets them live well with a serious illness. For hospice it's about making the most of precious time.

What is Palliative Care?

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 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.



Is Palliative Care Right for You?

Answer the following questions to determine whether palliative care might be right for you or someone close to you. Remember, you can receive palliative care at any point in your illness.

1. Do you have one or more serious illnesses such as: Cancer Congestive heart failure (CHF) Chronic obstructive pulmonary disease (COPD), emphysema, lung disease Kidney failure Liver failure Neurological diseases (e.g., ALS, Parkinson's) Dementia ○ Yes ○ No

Empower Patients and Families

Present Choices for Every Step

Emphasizing that people have choice engages the public because it tells them that they can have some control. Notably, in our focus groups, people were clear that they weren't interested in choices that weren't realistic, or weren't proven. But talking with doctors who gave them only one way forward made these savvy consumers suspicious that they weren't being told the whole story.

Educating through Stories

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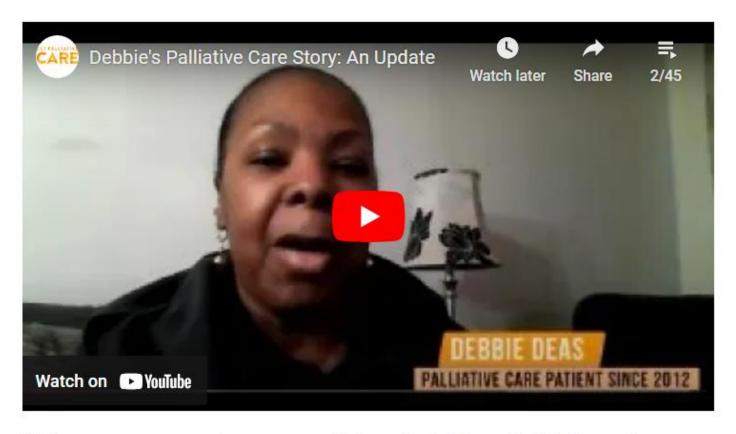
Use Positive Stories

People told us again and again that they learn better through stories. A well-chosen story helped them understand the types of care we were talking about in a way they could visualize. Statistics -- even statistically significant -- did not have the same impact. People connect to stories by seeing themselves in the story. And the story can talk about the benefits in a way that can show enough detail to be real and compelling. The most effective messages are based on stories that people would like to live out themselves, or contain lessons that speak to them.



How Palliative Care Has Helped Debbie Who Lives with Multiple Myeloma

FEB 28, 2024 / SHARE <



It's been over 10 years since we recorded our first video with Debbie, and we are happy to report that she is doing well. In the summer of 2022, Debbie agreed to join us for another video to talk about how palliative care has helped her.

Emphasize Communication

What to Expect from Your First Palliative Care Meeting

SEP 19, 2023 / SHARE <\$





You will get to ask questions

Palliative care is a two-way relationship between you and your health care team. In every meeting, you can ask any questions about palliative care, about your illness, and about your treatment options. Here are some suggestions of what to ask in your first meeting.

You will be at the center of your care

Palliative care is patient-centered, which means that the team wants to hear your story. In addition to addressing your pain and other symptoms, they will give you the chance to discuss how your illness is affecting your life. You will also be able to talk about any fears or anxieties surrounding your illness, treatments, or medications.

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Invite Dialogue, and Not Just Once

For a layperson, the idea of a two-way, back-and-forth conversation about serious illness was comforting and trust-building. The public idea of a serious illness conversation is hearing from a clinician you've never met before that you have to pull the plug on someone you love. Counter that fear by messaging that the heart of serious illness care is a two-way conversation.

Building a Team to Support Patients



Palliative Care Helps the Caregiver, Too

NOVEMBER 11, 2023



If you are caring for someone receiving you should know that the palliative car

Invoke a New Team

For most laypeople, having a team for their care is reassuring -- it means there is someone they'll be able to reach, and a lot of expertise. They don't know that palliative care and hospice are team-based. And they recognize that care needs often go beyond the medical team -- the real team might include someone from a faith community, or a meals on wheels, or a social service navigator. The most engaging messaging recognizes this reality, that living with a serious illness requires more than just healthcare.



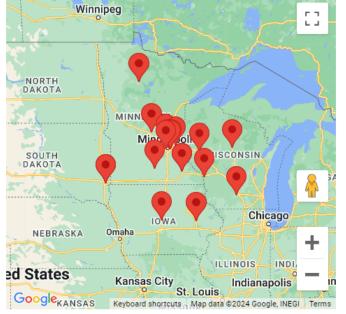
Palliative Care Provider Directory

Search Results: 20 results found

ENTER ADDRESS, ZIP CODE OR CITY & STATE
55116
CHECK THE ONE THAT APPLIES: ☑ Hospital □ Nursing Home □ Office/Clinic □ Home

Not Just Information: Options





https://getpalliativecare.org/provider-directory

Going Where the Information is Needed

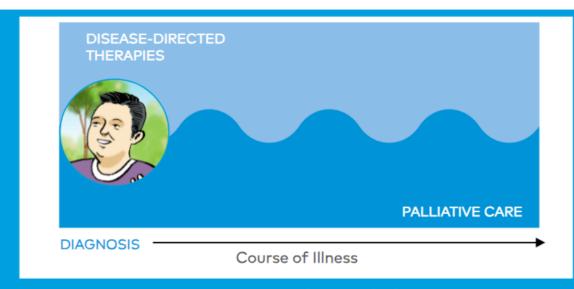
- Wikipedia pages for specific illnesses
- Patient advocacy and support organizations
- Printable, customizable brochures and one-pagers for patients and families



Introduction to Palliative Care for Health Professionals

Educating Health **Professionals**

Palliative care throughout the course of serious illness:



Mike receives pain management alongside his curative treatment for head and neck cancer, with the goal of continuing to work and support his family.



Key Resources

- → GetPalliativeCare.org
- → Palliative care provider directory
 - →(If you haven't listed your program...please do!)
- → Patient stories blog
- → Introduction to Palliative Care online course
- → Messaging tools for health professionals



