

## PALLIATIVE CARE CASE OF THE MONTH

# "Making a Referral to Specialty Palliative Care" by Karl Bezak, MD

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Case: Mr. B is a 72-year-old man with a history of chronic obstructive pulmonary disease on two liters per minute of oxygen at home, depression and anxiety who was admitted for chest pain and shortness of breath. You meet with him and his daughter at the bedside and share that his workup did not show anything serious; they seem somewhat relieved, but still appear worried. Mr. B shares that he has been unable to sleep at night and feels short of breath during the day, even when his oxygen levels are normal. He is chronically tired, his appetite is poor, and he has not been able to move his bowels for a week. His daughter, who cares for him, is concerned that nothing seems to help him feel better, and he is suffering. You ask if it would be all right to consult palliative care, and they appear confused. They ask what "palliative" is and why you are asking them, since "you're the doctor."

## **Discussion: Primary and Specialty Palliative Care**

There are two "flavors" of palliative care: primary and specialty palliative care. All clinicians who aim to reduce suffering and improve quality of life for patients and loved ones are practicing primary palliative care. These clinicians often follow the palliative care approach of "meeting the patient and loved ones where they are" and "walking alongside them" on their illness journey. Such support aims to alleviate pain and suffering and to prolong living in a personally meaningful way. Palliative care is the essential paradigm of what it means to care for patients with serious illness, their loved ones and caregivers on an individual and population level. Attainment of solid primary palliative care skills in basic symptom management and communication to build trusting relationships, as well as to develop goal-concordant care plans for patients with serious illness in routine scenarios, should be a professional goal of all clinicians who care for such populations and an essential part of medical and allied health education.

Physicians who have undergone fellowship training after their general training in any of eleven primary specialties (including internal medicine, family medicine, pediatrics, emergency medicine, surgery, obstetrics and gynecology, psychiatry, neurology, radiology, physical medicine and rehabilitation, and anesthesiology), practice specialty palliative care.1 Specialty palliative care, like primary palliative care, has the same philosophy and approach and is indicated for patients with serious illness who have refractory symptoms and/or complex biopsychosocial situations and existential suffering. Depending on the clinical situation one is facing, involving specialty palliative care for additional support can be helpful in meeting the goals of care for the patient, loved ones, and you as a clinician. Referral to specialty palliative care is often available in the hospital, in the clinic, and at home.

## How to make a proper referral: Describe specialty palliative care in the context of the patient's clinical state.

It is important to present palliative care referral to patients in a way that is patient-centered, aligns with their goals of care and promotes patient and loved one engagement in that recommendation. It is helpful to describe well the reason and positive value that a palliative care referral can have on the patient and loved ones' quality of life. Framing and focusing on the indication for referral such as uncontrolled pain, stress, or poor quality of life and recognizing specialty palliative care providers as a partner in care, are effective in introducing a referral to palliative care. Given that 71% of adults in the United States have never heard of palliative care2 and information available on the internet often describes palliative care alongside hospice care, unless the referral is put in context of their personal medical and biopsychosocial situation, a patient may mistakenly think that you are recommending end of life care when you hope to prolong a meaningful and enjoyable life despite serious illness.

## How to make a proper referral: Don't ask for permission.

Would you ask a patient having an acute myocardial infarction if it would be all right to consult cardiology? A referral to palliative care is indicated for patients with serious illness who are experiencing refractory symptoms, suffering and/or need assistance with complex medical decision-making (e.g., goals of care conversations). No permission is needed from the patient or loved ones to consult palliative care.

## How to make a proper referral: Stay informed and stay relaxed.

As usual, we should inform patients and their loved ones that a consultant will be coming to see them as we would for any other specialty. Given the common lack of understanding about what palliative care is and the large amount of confusing and misleading information available on the internet, it is vitally important to become comfortable describing palliative care. Your patients look to you as their clinician for accurate information and perspective, and if you are uncomfortable, they will be too. Box 1 contains an evidence-based definition of palliative care that has been validated as effective.3 Table 1 contains additional phrases with verbiage that you can combine based on the clinical situation, context, and which feels most authentic to you.



# **Box 1: Evidence-based definition of palliative care Center for the Advancement of Palliative Care (CAPC)**

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.

# <u>Table 1: Describing Specialty Palliative Care (Combine one from List 1 with one from List 2)</u>

List 1: Who Specialty Palliative Care Is	List 2: What Specialty Palliative Does
Specialists	To improve your symptoms
Consulting team	To help you feel better
Essential layer of support	To improve your experience in (care setting)
Partners in care	To reduce your stress and suffering
Interdisciplinary Team	To improve the quality of your life
	To walk alongside you in your illness journey

## Making a Referral to Specialty Palliative Care, Done Right

After Mr. B shares concerns regarding his numerous uncontrolled symptoms and his daughter shares her concern that he will never feel better, you take a moment to pause. You validate their concerns and provide empathetic statements that show you care about them and what they are experiencing. You then recognize that they would benefit from receiving additional support and trying additional therapies to improve the quality of their journey through serious illness. You mention a specialist team in the hospital that you partner with who might be able to help him feel better and recommend a palliative care consult. They agree and thank you for being kind and supportive.

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