PALLIATIVE CARE: SUPPORT FOR THOSE WITH SERIOUS, LIFE-THREATENING ILLNESS AND THEIR FAMILIES
Does This Sound Familiar?

- Your friend states that he has a “terminal” illness and the doctors have said, “there is nothing else we can do for you.”
While there may not be any curative treatments available, palliative care can provide many options to improve your friend’s quality of life.

For example......

- Address physical and psychological symptoms
- Explore spiritual/existential angst
- Provide grief/bereavement services for family
- Support caregiver
What Is Palliative Care?

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

~World Health Organization (WHO)
“Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.”

~Center to Advance Palliative Care (CAPC)
What Does Palliative Care Do?

- Addresses suffering
  - Physical, psychological, spiritual/existential

- Improves quality of life
  - Assess/manage pain and other symptoms

- Provides a team approach to care
  - Patient and family decide what THEIR goals of care are (not the healthcare team)

- Promotes excellent communication, allowing patient and family to make good decisions about care
DID YOU KNOW?

- When palliative care is introduced appropriately, **90% of Americans** state they are “very or somewhat likely” to consider palliative care for a loved one if they had a serious illness.

*2011 Public Opinion Poll*
How Does Palliative Care Differ From Hospice?

HOSPICE

- Patient considered “terminal” with less than 6 months to live
- Patient/family chooses NOT to receive aggressive, curative care
- Focuses on “care” versus “cure”
- Expenses are covered by Medicare, Medicaid, and most private health insurers

PALLIATIVE CARE

- Ideally begins at the time of diagnosis of a serious illness
- No life expectancy requirement
- Can be used to complement curative care
- Expenses are covered by philanthropy, fee-for-service, direct hospital support
- For pediatric patients, care is provided through mandates from the Affordable Care Act
Palliative Care Is Committed To…….

- Providing interdisciplinary care that promotes attention from a variety of healthcare professionals (nurse, physician, social worker, chaplain, pharmacist, etc.)

- Promoting the family as the unit of care
Respecting and honoring the patient’s culture

Providing care wherever patients receive treatment(s)
- Clinics
- Hospitals
- Homecare
- Nursing Homes
- Etc.
Palliative Care Is Committed To... (continued)

- Promotes excellent communication, allowing patient and family to make good decisions about care
  - Heart failure
  - Dementia
  - Respiratory, renal disease
  - Amyotrophic lateral sclerosis (ALS)
  - Others

- Caring for the whole person (physical, social, psychological, spiritual)

- Providing bereavement services
Let’s Look at Some Examples of How Palliative Care Can Assist Real Patients and Their Families
Lakeisha Was Born Yesterday

- Born with several physical problems—heart defect, kidney malformations, and abnormal platelets that do not clot her blood
- The team caring for Lakeisha believes her problems are so severe that she will die in the next few hours/days
- Her parents are devastated
- There are three other children at home under the age of 8.
WHAT PALLIATIVE CARE CAN PROVIDE FOR LAKEISHA AND HER FAMILY

- Clarify/respect goals of care (asking the family what their goals of care for Lakeisha)
- Assist healthcare team with any untoward symptoms (e.g. shortness of breath, pain, etc.)
- Provide attention to siblings from child life specialist
- Special attention to the mother, who is recovering from delivery and now in grief
- Provide interdisciplinary support to the family
- Memory-making (e.g. taking pictures, hand/feet prints, etc.)
Jonathan: A Bike Accident

- Jonathan, age 12, was hit by a car while going to school.
- Was medevac'd to a large inner-city hospital 150 miles from home.
- His single mom drives alone to the hospital to be with her son.
- She arrives in the emergency room and is told to sit out in the waiting room – she sits alone.
What Palliative Care Can Provide for Jonathan and His Mother

- Provide a palliative care team member for Jonathan’s mother who is sitting alone in the waiting room
- Listen to her fears
- Up-date the mother as frequently as possible about Jonathan’s condition
- Make calls to other supports (e.g. family, chaplain, etc.)
MONICA: YOUNG MOTHER WITH COLON CANCER

- 36-year-old mother of four young children
- Diagnosed with stage 4 colon cancer 6 months ago
- Experiencing nausea/vomiting, fatigue, weight loss, and anxiety associated with her chemotherapy
- Her husband, Mark, has his own business – if he misses work, he does not get paid
- No family in the area to assist with child care or visits to the cancer center to receive chemotherapy
- Monica thinks about what would happen to her children if she dies
- Spiritually, she wonders if God is punishing her
WHAT PALLIATIVE CARE CAN PROVIDE FOR MONICA AND HER FAMILY

- Provide interdisciplinary care to address and manage symptoms (nausea/vomiting, fatigue, weight loss, anxiety)
- Address goals of care
- Provide attention to the children through use of a child life specialist
- Have social worker address financial and childcare concerns
- Chaplain visit to discuss her concern that God may be “punishing” her
- All members of the team would meet frequently to discuss on-going care for Monica and her family
ARThUR: HEART FAILURE, HYPERTENSION, AND DIABETES

- 78 years old, experiencing heart failure and uncontrolled diabetes over the past 3 years
- He is the sole caregiver to his wife of 55 years, who has Alzheimer’s
- Four adult children live out-of-state
- In the past 6 months, he has had four ER visits and three hospital admissions
- No advanced directive
- Lives in rural America with poor access to care
- Veteran, with a history of PTSD
WHAT PALLIATIVE CARE CAN PROVIDE FOR ARTHUR AND HIS FAMILY

- Provide interdisciplinary care to address and manage symptoms (shortness of breath, fatigue, anxiety related to PTSD, etc.)
- Social work consult to assist in caring for wife
- Discuss the urgent need for an advanced directive, along with his goals of care
- Explore the following:
  - Commitment of any of the four children to assist with care?
  - Is it safe to send Arthur back home?
  - Are there any Veterans benefits for which Arthur could qualify regarding further/future care?
Most Frequently Asked Questions
How Do I Know If I Need Palliative Care?

- A need for symptom management (i.e. pain, nausea, vomiting, anxiety, fatigue, etc.)
- Assistance with making difficult medical decisions
- Address spiritual issues
- Assistance in addressing practical needs for both patients and their families
- If death is imminent, obtain information on how to maximize opportunities for personal growth (e.g. saying “I love you,” “I forgive you,” “I will miss you,” etc.)
- Desire for bereavement care for family members
HOW DO I TALK WITH MY HEALTHCARE PROVIDER ABOUT PALLIATIVE CARE?

- Sometimes, your healthcare providers (HCP) are reluctant to offer palliative care, as they believe it means they are “giving up” on you.

- Let your HCP know that you want a palliative care consult—specifically stating what your needs are (worsening pain and other symptoms, spiritual, emotional issues, etc.).

- Refer to your plan of care—remind your HCP of YOUR goals of care.

- Ask for a second opinion, if needed.
Can I Keep My Primary Care Provider If I Choose to Have Palliative Care?

- **YES!**
- Think of it this way....
  - Palliative care is not an “add on” to your care when all else fails, but rather complements care you already are receiving from your primary care provider.
  - Just as your primary care provider would contact a cardiologist if you had a heart problem, your provider would contact a palliative care professional to assist with your care.
HOW MUCH EXTRA DOES IT COST IF I CHOOSE PALLIATIVE CARE?

According to data from a 2008 study, for those who received palliative care:

- There was a savings of $\textbf{1696}$ in direct costs per admission ($279$/day), compared with usual care (for those who were discharged from the hospital)

- There was a savings of $\textbf{4908}$ in direct costs per admission ($374$ a day), compared with usual care (for patients who died in the hospital)

**WHY THESE LOWER COSTS?**
Fewer laboratory/diagnostic tests and medications were ordered, less intensive care admissions

*Physician and APRN visits usually are billed to your insurance. Other services are often free of charge.  
Morrison, 2008*
Is There a Research Study That Supports Palliative Care? YES!

- When compared to standard/non-palliative care, patients newly diagnosed with metastatic non–small-cell lung cancer who received palliative care reported:
  - Better quality of life
  - Fewer reports of depression
  - Median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months for those receiving standard care)

(Temel et al., 2010)

Note: Several other studies support this data.
SOME RESOURCES

- Aging With Dignity—5 Wishes  
  http://www.agingwithdignity.org/five-wishes.php

- Next Step in Care: *Family Caregiver’s Guide to Hospice and Palliative Care*  

- National Caregivers Library: *Hospice versus Palliative Care*  
Q & A?
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REFERENCES


