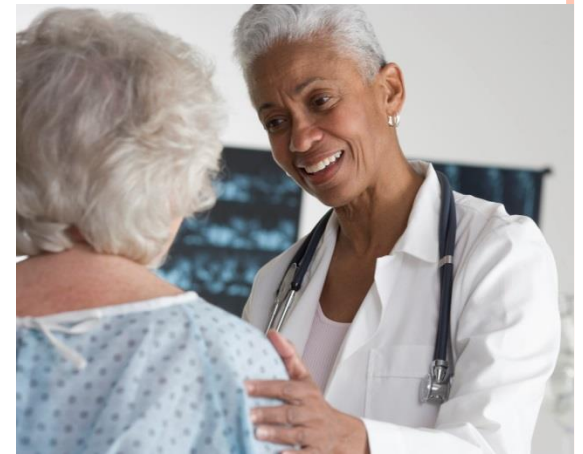
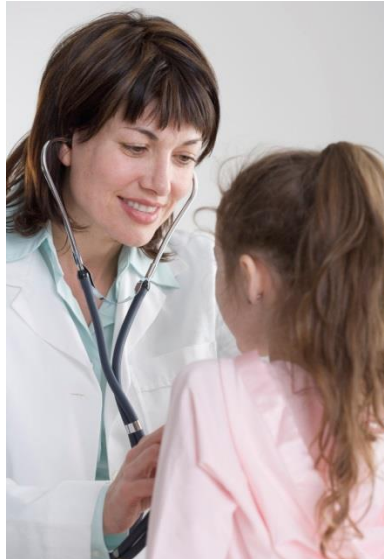


PALLIATIVE CARE: SUPPORT FOR THOSE WITH SERIOUS, LIFE-THREATENING ILLNESS AND THEIR FAMILIES



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)



WHAT IS PALLIATIVE CARE? (CONTINUED)

- “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?

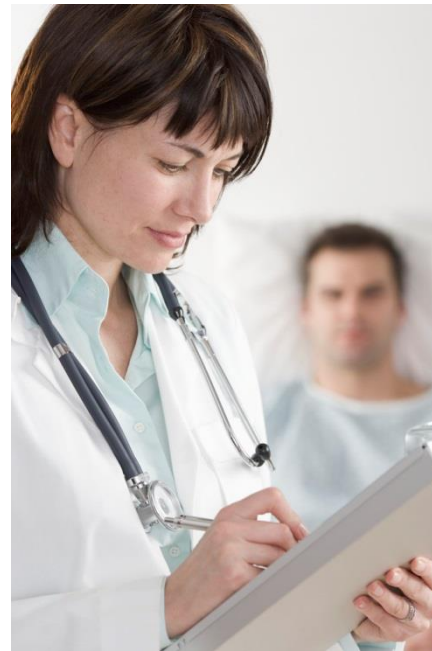
- Addresses suffering
 - Physical, psychological, spiritual/existential
- Improves quality of life
 - Assess/manage pain and other symptoms
- Provides a team approach to care
 - Patient and family decide what THEIR goals of care are (not the healthcare team)
- Promotes excellent communication, allowing 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



PALLIATIVE CARE IS COMMITTED TO...(CONTINUED)

- 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

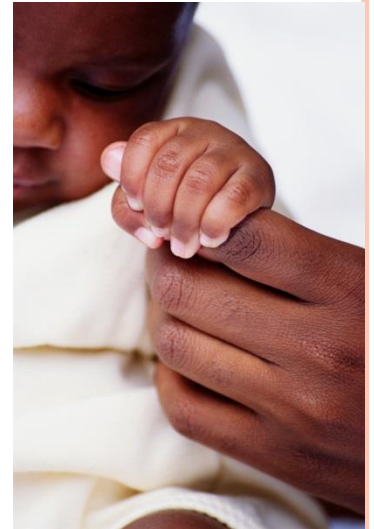


LET'S LOOK AT SOME EXAMPLES OF HOW
PALLIATIVE CARE CAN ASSIST REAL PATIENTS
AND THEIR FAMILIES



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



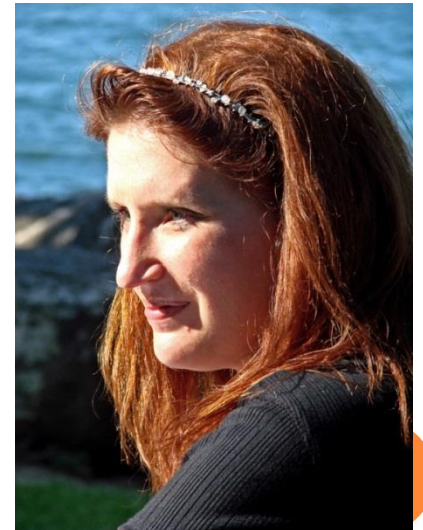
WHAT PALLIATIVE CARE CAN PROVIDE FOR JONATHAN AND HIS MOTHER

- 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



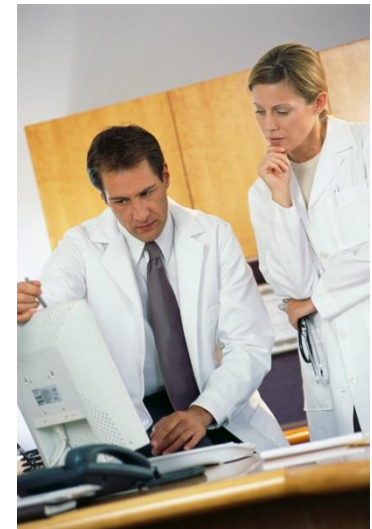
HOW DO I TALK WITH MY HEALTHCARE PROVIDER ABOUT PALLIATIVE CARE?

- 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 provide
 - 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 **\$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 **\$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*

<http://www.nextstepincare.org/uploads/File/Guides/Hospice/hospice.pdf>

- National Caregivers Library: *Hospice versus Palliative Care*

<http://www.caregiverslibrary.org/caregivers-resources/grp-end-of-life-issues/hsgrp-hospice/hospice-vs-palliative-care-article.aspx>



Q & A?





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REFERENCES

- *2011 Public opinion research on palliative care: a report based on research by public opinion strategies*. New York, NY: Center to Advance Palliative Care; 2011. Available at: <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>. Accessed May 16, 2014.
- Center to Advance Palliative Care (CAPC). <http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc>. Accessed May 16, 2014.
- Morrison, RS, Penrod, JD, Cassel, JB, Caust-Ellenbogen, M, Litke, A., et al., (2008). Cost Savings Associated With US Hospital Palliative. *Arch Intern Med*. 2008;168(16):1783-1790.
- Temel, JS, Greer, JA, Muzikansky, A., Gallagher, ER, Admane, S., et al. (2010). Early palliative care for patients with metastatic non–small-cell lung cancer. *New England Journal of Medicine*; 363:733-742. doi: 10.1056/NEJMoa1000678.
- World Health Organization (WHO). <http://www.who.int/cancer/palliative/definition/en/>. Accessed May 16, 2014.

