# **PALLIATIVE CARE**

Brought to you by the Massachusetts Medical Society and its Committee on Geriatric Medicine

### What is palliative care?

Care focused on helping support and guide patients who have life limiting and serious illnesses, as well as their families and caregivers

#### **Palliative care:**

- is for people with life limiting and serious conditions
- addresses physical, emotional, spiritual and psychosocial distress
- is usually provided by a team of doctors, nurses, and social workers, and sometimes includes physical therapists, nutritionists, chaplains, or other professionals
- seeks to improve quality of life for the ill person and his or her family
- matches patient values and preferences to achievable health care goals in order to develop and direct an individualized plan of care

# Palliative care

Became a specialty in 2006 Grew out of hospice

#### Focuses on three domains:

- pain and symptom management (includes, but is not limited to, nausea, delirium, constipation, dyspnea, anorexia)
- psychosocial and spiritual support
- advance care planning

# Palliative care

- can be helpful for patients of ALL ages:
  - $\circ$  at the time of diagnosis of a serious illness
  - in concurrence with curative treatments for life-limiting problems
  - $\circ$  living with chronic diseases
  - $\circ$   $\,$  nearing the end of life

### Palliative care can be provided in any setting

- very common in larger hospitals and some smaller ones
- outpatient ambulatory centers such as pain and symptom management centers
- nursing facilities
- at home (near the end of life, hospice is most commonly used)

# The role of primary care in palliative care

- much symptom and pain management is already being addressed
- educate patients and families about palliative care
- assist patients and families with advance care planning

#### When the patient's needs exceed the PCP's capabilities

- know how to get extra support and help
- cultivate a clinical relationship with a palliative care team or provider who can offer consultation or care management support
- know the resources in your community
- provide materials in hand or on-line resources to patients
- recognize many PCP practices do not have resources for spiritual and psychosocial support

# What is Hospice?

- a Medicare benefit since 1986
- designed for those with less than 6 months to live should the disease run its natural course
- a specific form of palliative care supplied by an agency
- the most widespread, developed way to provide palliative care for patients at or approaching the end of life
- provided typically in home but also available at nursing homes, hospitals, or at a hospice residence
- can reduce the risk of depression in a spouse even when provided to the loved one a few days before death
- reduces the risk of the widow or widower from dying prematurely

# Hospice and Palliative Care Both:

- provide support to caregivers
- use an interdisciplinary team approach
- focus on pain management, psychosocial and spiritual support and advance care planning
- can be provided in any setting

### Additionally, hospice

- is similar to a traditional visiting nurse but has enhanced services to support patients with less than 6 months prognosis
- strives to keep patients home or in their current setting as they decline
- is for individuals with care goals focused on comfort
- provides bereavement services for 13 months post death

# Hospice and Palliative Care:

	Palliative Care	Hospice Care
•	Meant for those with serious illness; not limited by life expectancy	• A type of palliative care for those with six months or less of life expectancy; can be extended past six months, with certain criteria met
•	Individuals may still receive curative/disease modifying treatments	<ul> <li>Individuals no longer receive curative treatment; the focus becomes care that improves quality of life</li> </ul>
•	Eligible patients have a serious, life-limiting illness, including ALS, cancer, congestive heart failure, kidney failure, liver failure, COPD, dementia, and Parkinson's	• Eligible patients have up to a 6 month prognosis; can return to curative or disease modifying care trajectory as a primary goal but would typically then leave hospice.
•	Offered in any setting although most commonly offered in the hospital setting	Offered in any setting

# **Advance Care Planning:**

- allows patients to express their goals and values
- communicates those goals and values to clinicians and family
- designates a health care proxy in the event of incapacity

### An advance directive

- a document that specifies wishes for future care
- appoints a health care proxy
- may include medical orders (DNR/comfort care form or MOLST)

# Advantages of Advance Care Planning:

- prevents over-treatment and under-treatment
- assures the patient's wishes are known in the event of loss of capacity to make decisions
- prepares the groundwork for future decision-making

### Advance care planning components:

Health Care Proxy

- the only officially recognized Advance Directive in Massachusetts
- denotes health decisions in the event of incapacity
- communicates patients' life-sustaining treatment preferences
- medical orders if appropriate
  - Out-of-hospital DNR
  - MOLST

### **Communicating with Patients About Palliative Care**

Talking to patients about palliative care can be difficult, especially when patients do not understand what palliative or hospice care entail or know the differences between the two.

Determine if the patient has made advance care plans. If not:

- elicit and prioritize goals of care
- translate goals into a plan for care

Patients and families of patients considering hospice care need additional support, as they are dealing with many challenging decisions. Both palliative care and hospice care provide aggressive care aimed at optimizing symptom management.

# **Communicating with Patients About Palliative Care**

When planning the conversation, make sure to:

- determine what the patient and family understand about their illness or disease trajectory
- realize how well the patient and family are able to understand
- allow enough time for a thorough discussion

- be aware of who else will be present at the meeting
- remember most patients and families want honest, objective information
- encourage patients to designate a health care proxy
- a health care proxy form and instructions can be found at <u>www.massmed.org/proxy</u>

# Maintain An Inclusive Environment

- different cultures and religions deal with death and illness in different ways
- consider incorporating a chaplain or other religious figure into the care team
- be aware that some cultures take a community-based approach to decision making (family-inclusive decision making)
- consider hiring a translator who is familiar with medical terminology if language is a barrier
- avoid using a family member as a translator; they might be unfamiliar with medical terms, may translate incorrectly, or may leave out information to 'protect' the patient
- always offer silent listening and empathetic responses to emotions

# **Resources for Physicians**

- <u>Communicating Difficult News</u>: A presentation from the Massachusetts Medical Society's conference on palliative care; how to provide information and comfort to patients and families
- <u>Making Health Care Decisions for Others</u>: A presentation from the Albert Einstein College of Medicine that advises physicians on how to work with health care proxies and surrogates (pdf)
- CAPC Fast Facts and Tools for Providers:
- <u>VITAL Talk</u>: Nonprofit agency providing interactive clinician and faculty development courses to improve communication skills on an individual and institutional level
- <u>Dying In America</u>: The latest report on end of life information from the Institute of Medicine

# **Resources for Patients**

- <u>The Conversation Project</u>: This website includes a starter kit for beginning a conversation on values with loved ones
- <u>IOM Report The Conversation</u>: This website includes a myriad of resources and decision tools for patients and their families
- <u>Medline Plus</u>: This page answers common questions about palliative care for patients and families that need more clarification
- <u>End of Life</u>: A resource from the National Institute on Aging to guide caregivers through the end of life process
- <u>Get Palliative Care</u>: This website is a resource on palliative care, with more information on the process and a directory of palliative care centers by state
- <u>Hospice and Palliative Care Federation of MA</u>: This website provides more details on palliative and hospice care, as well as a directory of hospice care centers

# **Resources for Patients**

• <u>Planning Ahead: What Are Your Choices</u>: – this downloadable brochure describes end of life planning steps across the lifespan