

Palliative Care and Supportive Oncology for People Living with Waldenstrom's Macroglobulinemia

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Definitions

- Palliative Medicine
- Palliative Care
- Supportive Oncology



Palliative Medicine

Medical subspecialty

- Comprehensive care for patients with serious illness throughout the course
- Focus on pain and symptom management
- Attention to goals of care: facilitating communication and navigating decision-making
- Interdisciplinary team approach to support whole person with psychosocial and spiritual care
- Philosophy of patient-centered comprehensive care



How is Palliative Care different from hospice?

Hospice

- Medicare benefit (1982)
- Medical eligibility: <6 month prognosis
- Philosophical alignment: care directed towards symptoms; patient must choose
- Medicare pays hospice agency per diem
- Patient gets all medications, DME, staff visits (RN, CNA, SW, chaplain), 24-hour call
- Designed for symptom-based holistic End of Life Care

Palliative Care

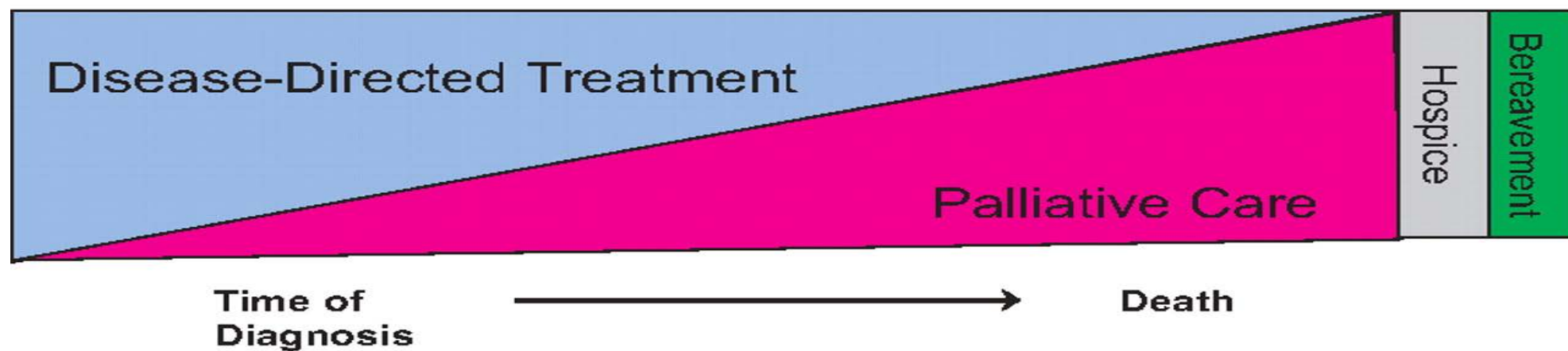
- Concurrent care, occurs anywhere during the course of illness
- Not limited to End of Life Care



Traditional Model for Patients with Advanced Illness Care



Integrated Care for Patients with Advanced Illness



Palliative Care

An approach to **patient/family/caregiver-centered** health care that focuses on:

- the optimal **management of pain** and other distressing symptoms,
- while incorporating **psychosocial and spiritual care**
- according to patient/family needs, values, belief and cultures.

The goal of palliative care is to:

- **anticipate, prevent and reduce suffering** and
- to support the best possible **quality of life** for patients/families/caregivers
- **regardless of the stage of disease or the need for other therapies.**

Palliative Care

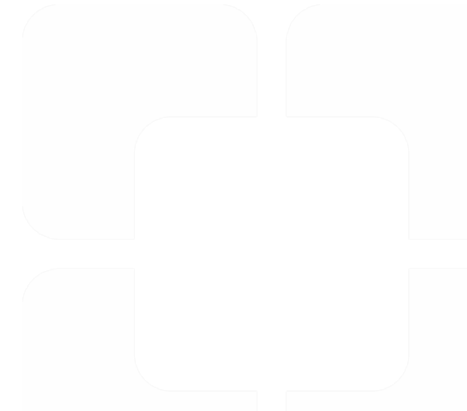
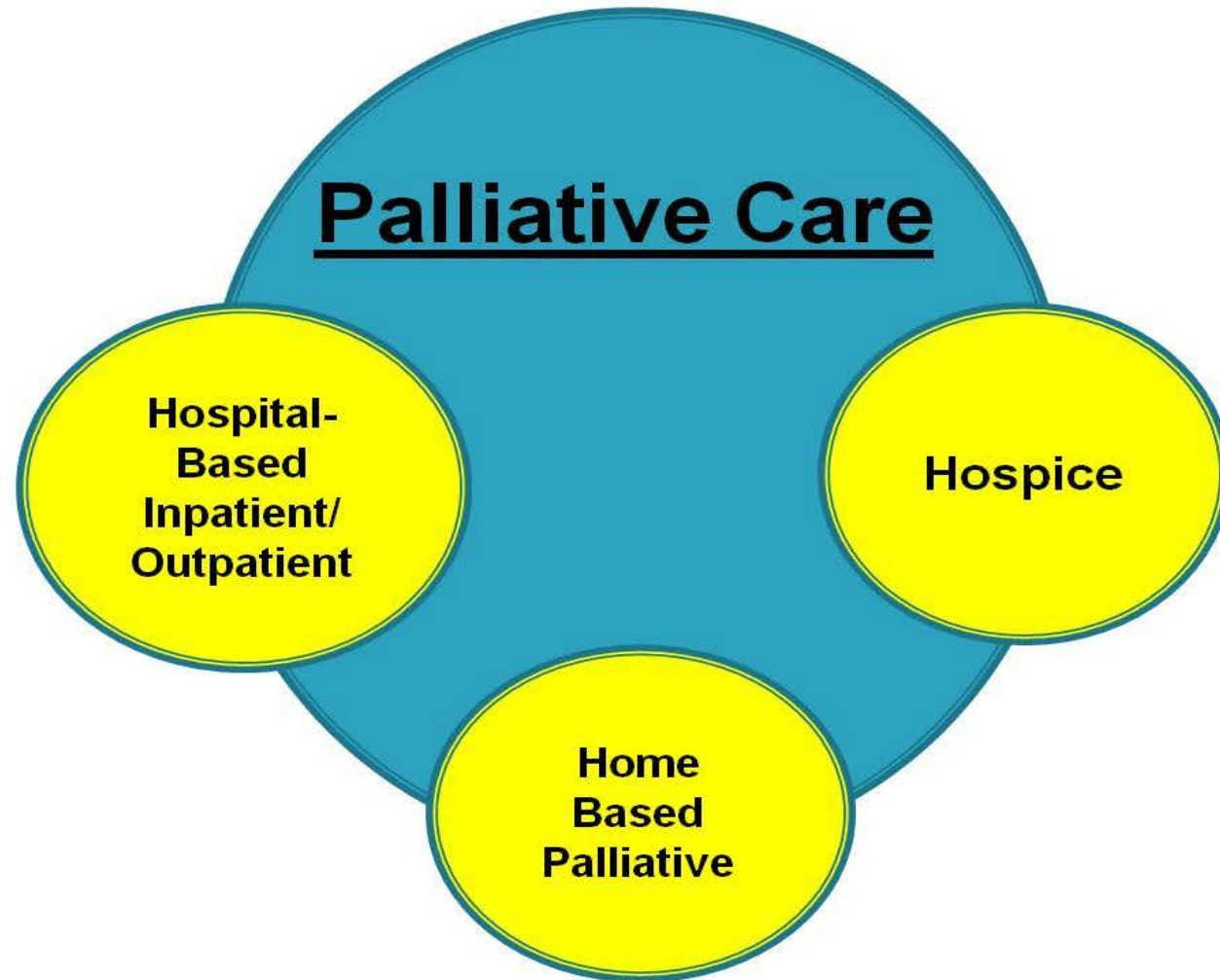
- Palliative care:
 - can begin at diagnosis
 - should be delivered concurrently with disease-directed, life-prolonging therapies
 - should facilitate patient autonomy, access to information and choice
- Palliative care becomes the main focus of care when disease-directed, life-prolonging therapies are no longer effective, appropriate or desired.
- Palliative care should be
 - initiated by the primary oncology team
 - and then augmented by collaboration with an interdisciplinary team of palliative care experts.

Palliative Care Specialists

- Physicians
 - Fellowship training
 - Board certification
- Advance Practice nurses, physician assistants
- Nurses (RNs)
 - Palliative care training and certification
- Social Workers
- Chaplains
- Pharmacists
- Behavioral Health



Spectrum of Palliative Care Services



Palliative Care

- Discuss anticipation and prevention of symptoms
- Clarify goals of care and purpose of treatment
- Discuss advance care planning
 - HC-POA
 - Living will
 - Code status



Waldenstrom's Macroglobulinemia

- Rare, indolent non-Hodgkin's lymphoma
- Elevated IgM levels, anemia, lymph nodes
- Variable symptoms and complications
- Risk for hyperviscosity, infections, peripheral neuropathy
- Chronic illness: observation, newer treatment options, long survival

Symptoms in WM

- Fatigue, lack of energy
- Fevers/chills/nights sweats
- Recurrent sinus, bronchial infections
- Peripheral neuropathy
- Bruising/bleeding
- Ocular complications
- Headaches, blurry vision, confusion (rare)
- Raynaud's (cryoglobulinemia)

Fatigue

- Common symptom in WM (up to 75%)
- Causes:
 - Anemia
 - Treatment-related
 - Multifactorial
- Treatment
 - Correct anemia
 - Medication (methylphenidate, American ginseng)

Peripheral neuropathy

- Sensory (up to 50%)
 - Numbness, tingling, pain, burning, stabbing, shooting
 - Often starts in toes/feets, hands
- Causes
 - IgM related (anti-Myelin Associated Glycoprotein)
 - Treatment related
 - Non-WM: diabetes, B12 deficiency
- Treatment
 - Treat underlying cause
 - Medications

Chemo-Induced Peripheral Neuropathy

- Common
- Affects QOL, functional status, balance
- May require dose reductions
- Primarily sensory, symmetrical, stocking-glove
- Tingling, numbness, burning pain
- Worse at night, better with firm shoes
- Cumulative
- May be partially reversible or permanent
- Rare autonomic neuropathy (dizziness, orthostasis, constipation, urinary retention)

Advance Care Planning

- Advance care planning
- Goals of care
- Advance directives
- Code status



La Crosse, WI

- Respecting Choices 1993
- Started by ethicist at Gunderson
- Community-based
- 90% AD rate
- 99% in medical chart
- 99% concordance with care



Advance Directives

- Health Care Power of Attorney
- Living Will
- Guardianship
- Portable DNR
- MOLST/POLST
- 5 Wishes



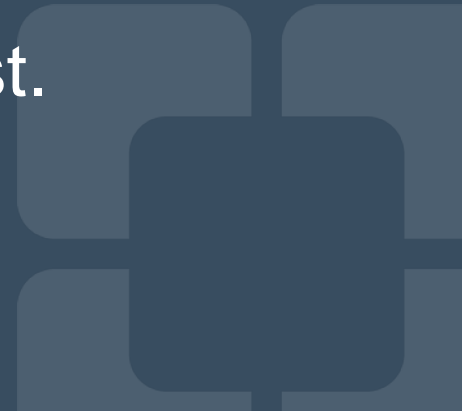
Ohio Law and Decision-Maker Hierarchy

- Spouse (even if separated)
- Adult Children (age >18) (majority)
- Parents
- Adult Siblings (age >18) (majority)
- Nearest blood/adoptive relative



Advance Care Planning

- Advance care planning is a process for understanding a patient's personal values, goals and preferences about future care
- Goals of care conversations are a similar process, focused on current care
- Advance directives are necessary but not sufficient to address care goals
- ACP honors the patient as a person and improves patient experience, quality metrics and reduces cost.



Key Takeaways

- Palliative care can be an added layer of support to address symptoms, quality of life, psychosocial issues, advance care planning
- Available and appropriate at all stages

