



MASSACHUSETTS  
GENERAL HOSPITAL

DIVISION OF PALLIATIVE CARE  
AND GERIATRIC MEDICINE

# Quality of Life and Interstitial Lung Disease: *The role of palliative care along the trajectory of illness*

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ILD Collaborative Community Meeting  
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# Disclosure

- I have nothing to disclose.



# Overview

- Review the differences between palliative care and hospice.
- Review how palliative care and hospice can help support a patient and family across the trajectory of ILD.
- Review how to access these services in the community.



# Palliative care versus hospice: Intertwined yet distinct

Palliative Care:  
Clinical Interdisciplinary Care  
Based on Need

Hospice:  
Insurance Benefit  
Based on Prognosis



# An interdisciplinary approach to care: Understanding the domains of suffering

## Physical:

- Disease management
- Symptom management
- Functional status

## Psychological:

- Coping in response to illness
- Dignity and control
- Managing grief and/or loss



## Social and/or Cultural:

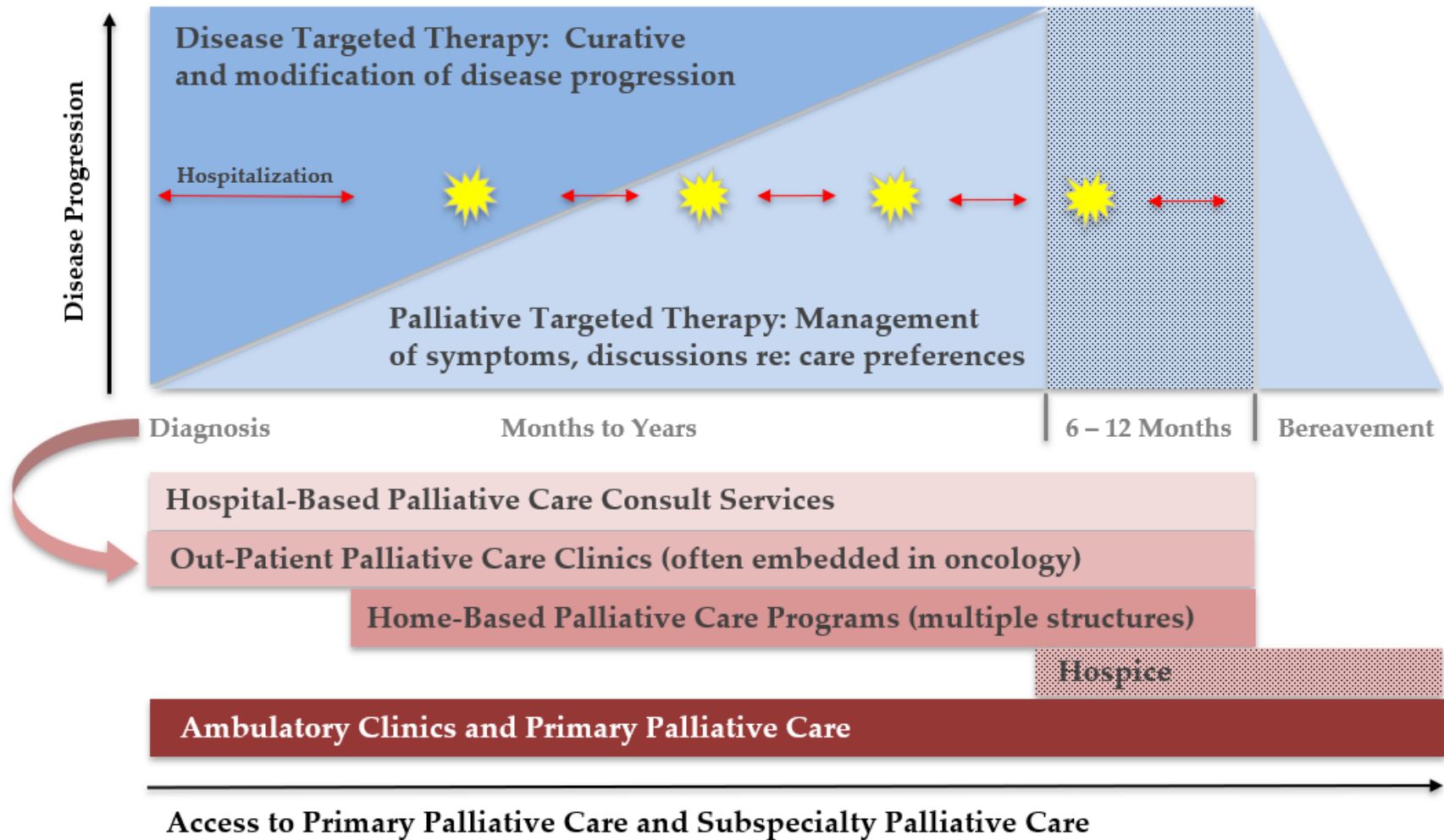
- Family/caregiver support
- Relationships
- Rituals, values

## Spiritual:

- Sense of meaning
- Existential questioning
- Life transitions



# Palliative Care: Accessing Primary and Subspecialty Palliative Care

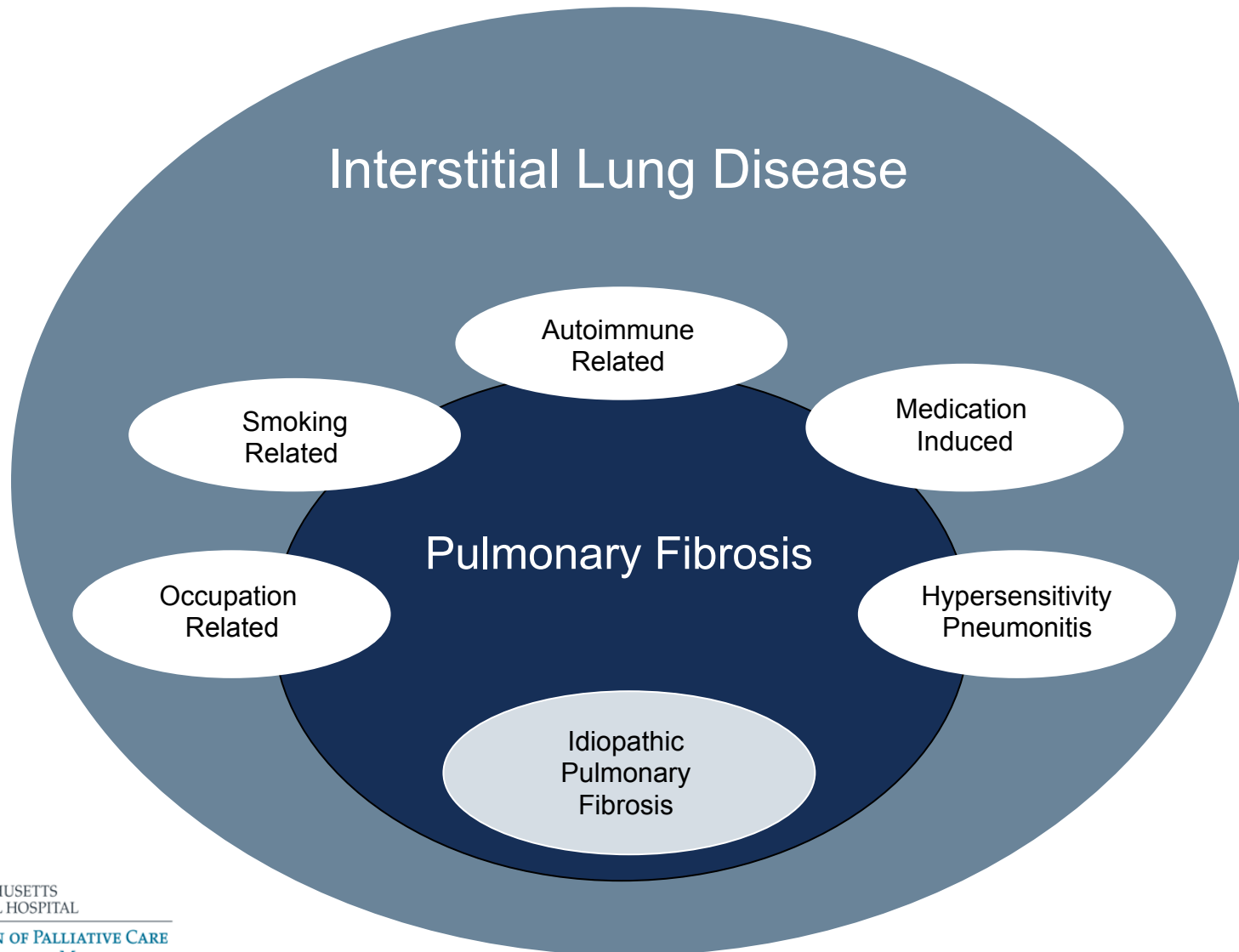


# Putting a conceptual fire wall between PC and Hospice: How might that be helpful?

- Despite advances, 2 out of 5 patients with heart failure will die within five years of their diagnosis.
  - Taylor, Clare J., et al. "Trends in survival after a diagnosis of heart failure in the United Kingdom 2000-2017: population-based cohort study." *BMJ* 364 (2019).
- Dementia is a life limiting illness with well understood markers of a shift to a shorter prognosis.
  - Sampson, E.L., et al., 2018. *Living and dying with advanced dementia: a prospective cohort study of symptoms, service use and care at the end of life. Palliative medicine*, 32(3), pp. 668-681.
- ILDs are a heterogenous group of disorders and pose diagnostic and prognostic challenges.
  - Guler, S.A., et al, 2018. Heterogeneity in unclassifiable interstitial lung disease. A systematic review and meta-analysis. *Annals of the American Thoracic Society*, 15(7), pp.854-863



# Putting a conceptual fire wall between PC and Hospice: Managing diagnostic and prognostic uncertainty...and symptoms





# Serious Illness and GOC Conversations: Intertwined yet distinct

- **Serious Illness Conversations**
  - Take place longitudinally.
  - Explore illness understanding, hopes/worries and goals/values.
  - Clarify what matters most to a patient should their health worsen.
- **Goals of Care Conversations**
  - A medical decision that needs to be made in response to a change in a patient's clinical status or to a shift in a patient's goals/values.

Schulz, VM et al. "Beyond Simple Planning: Existential Dimensions of Conversations With Patients at Risk of Dying From Heart Failure." JPSM 2017.



# The Relationship:

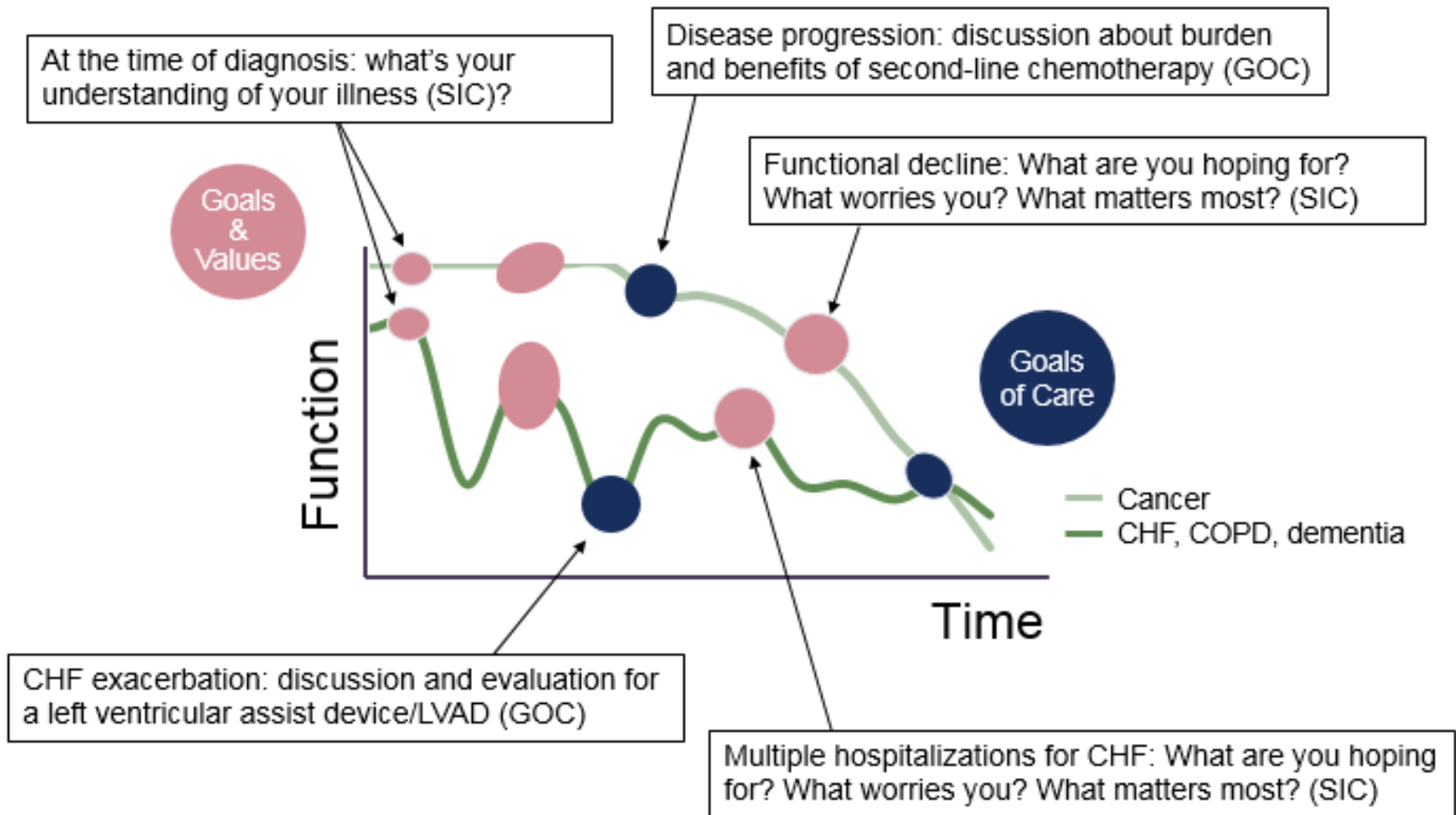
## Serious Illness and Goals of Care Conversations

Serious Illness:  
Exploring Goals/Values and  
Hopes/Worries *Longitudinally*

GOC:  
Medical Decision  
Making at a  
*Point in Time*



# The Relationship: Serious Illness and Goals of Care Conversations



# Earlier conversations about patient values and goals: The link to better ~~serious illness~~ care

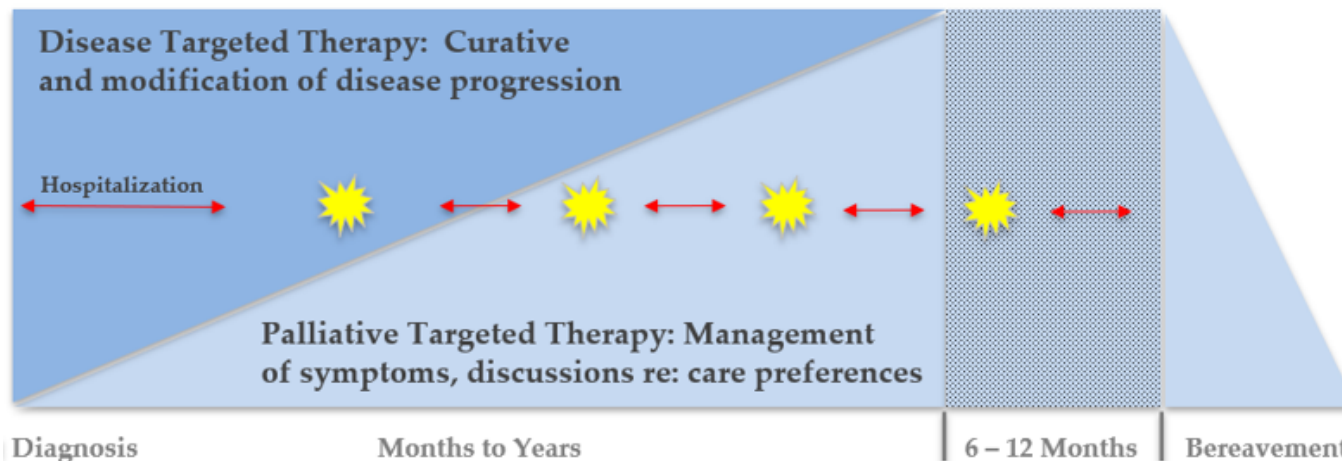
- Increased goal-concordant care
  - Understanding what matters most when talking about clinical decision making (medications, starting O2, trials)
- Improved quality of life and patient sense of well-being
  - Addressing each of the domains of suffering
- Better patient and family coping
  - Lower rates of depression and anxiety
- Fewer hospitalizations
  - Anticipatory planning for expected clinical complications
- More frequent and earlier enrollment in hospice care
  - Anticipatory planning for when disease modifying therapies are no longer providing benefit

Mack JCO 2010; Wright JAMA 2008; Chiarchiaro AATS 2015; Detering BMJ 2010; Zhang Annals 2009



# Involving subspecialty Palliative Care: Where along the trajectory of illness and by whom?

- Where along the trajectory of illness?
  - Well...
    - I would say at the beginning with an introduction as part of the care team although we're not there yet.
  - Second best option:
    - if hospitalizations increase, medications stopped or adjusted because not as effective, initiation of O2.



# Involving subspecialty Palliative Care: Where along the trajectory of illness and by whom?

- By whom?
  - Hospital-based:
    - Symptom management, clarify goals/values, community resources.
  - Clinic-based:
    - Most palliative care clinics are (currently) embedded in oncology although they may be able to accommodate a handful of visits.
  - Home-based:
    - Available resources not well understood which leads to confusion;
    - Most programs are a part of a home health or hospice agency.
      - The MGB HBPaIC Program is NOT part of home health or hospice. MGB HBPaIC is a clinical service line within the MGH Division of Palliative Care and Geriatric Medicine.
      - The Hospice and Palliative Care Federation of MA (HPCFMA) has a hospice locator on its website, and you can select for palliative care and town to find resources.
    - There is NO home-bound requirement. Some programs are linked to an agency's home health services which do require a patient to be homebound.



**Thank you:**  
**Questions, thoughts?**

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