



NJ Palliative Care
SOLUTIONS

When Cure Isn't Possible: Delivering High Quality Palliative Care in Neurosciences

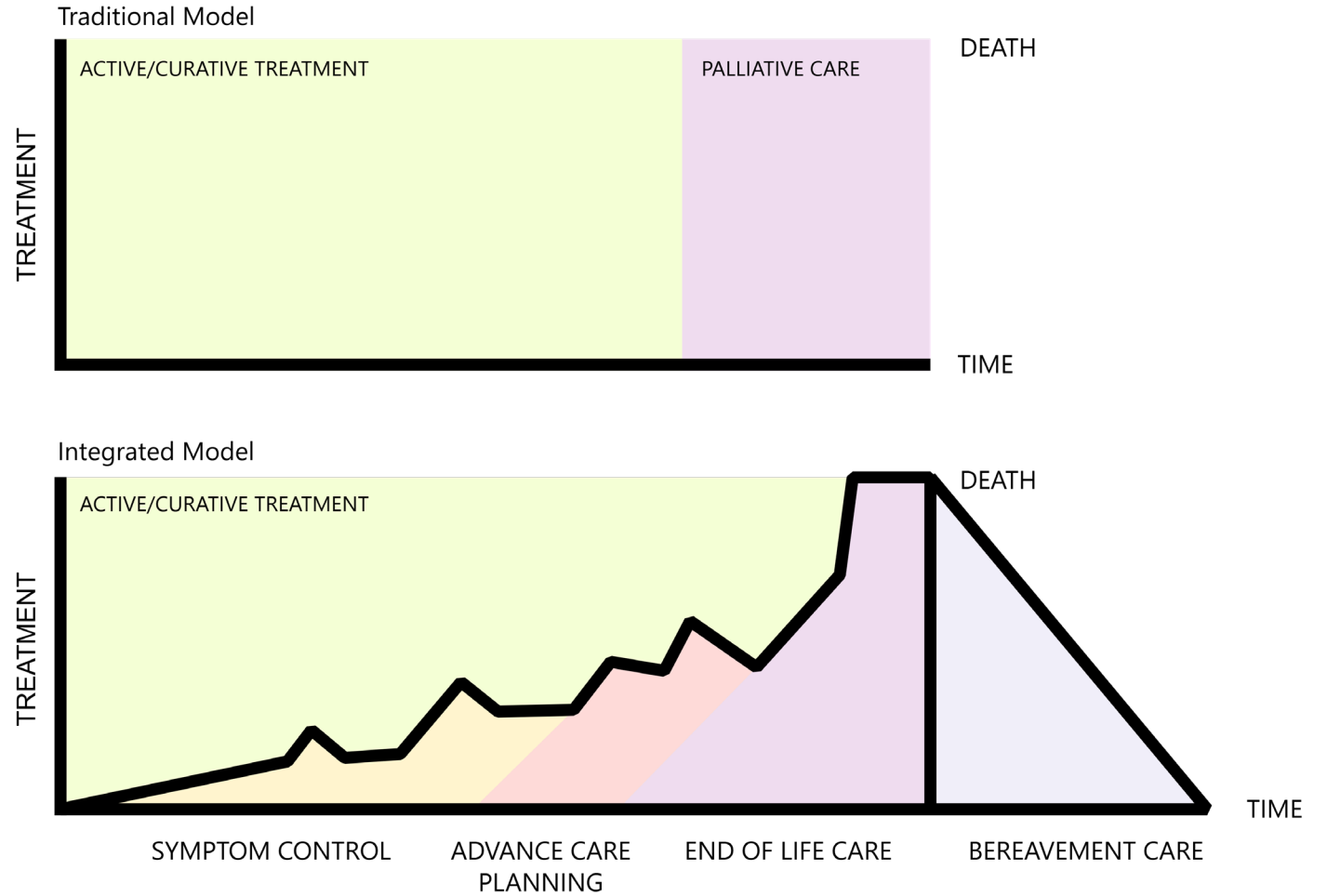
Jessica L. Israel MD

Chief Medical Officer, NJ Palliative Care Solutions

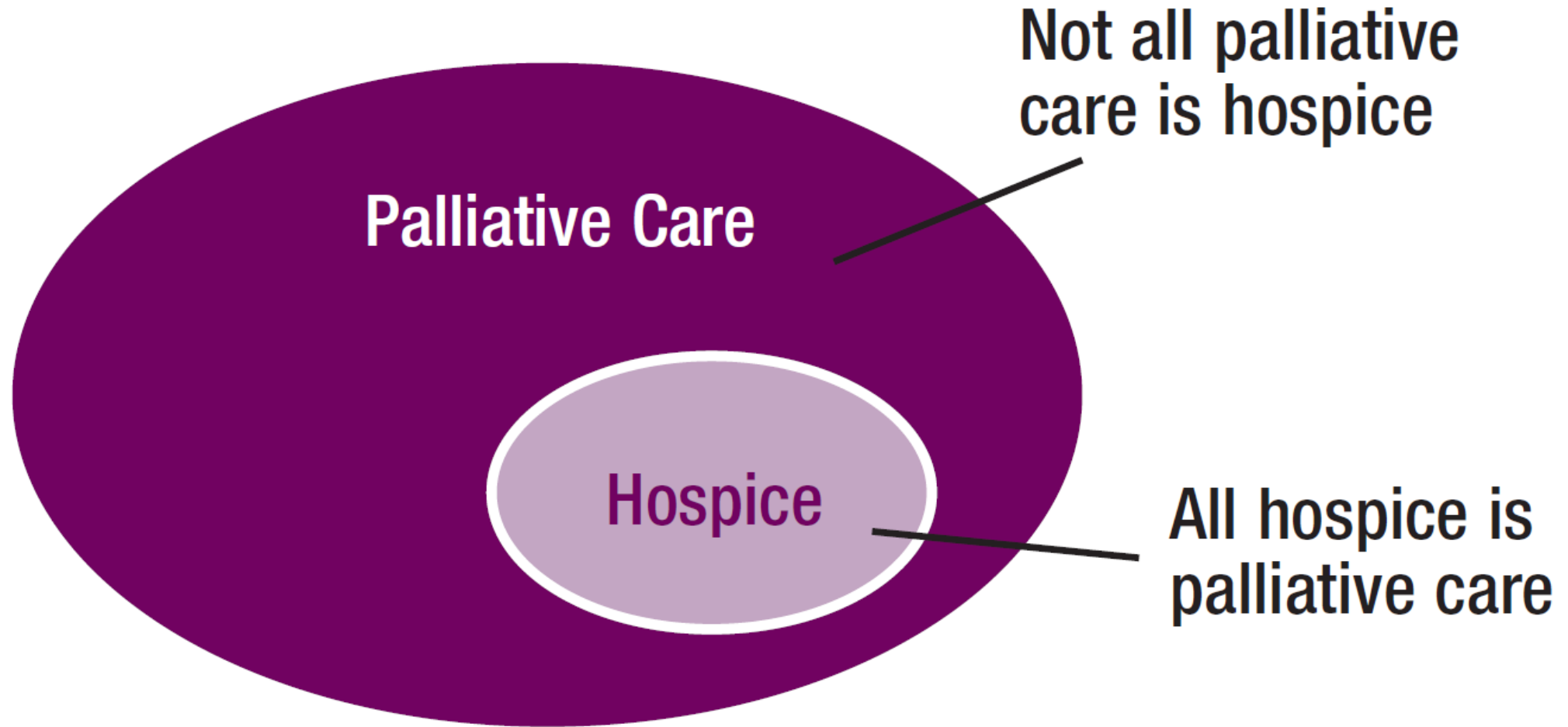
Chief Medical Officer, Executive Vice President, Complete Care



Defining Palliative Care



PALLIATIVE CARE	HOSPICE CARE
 Care Timing anytime after diagnosis	 final months of life
 Primary Goal improve quality of life	 comfort in end-of-life
 Care Setting hospitals, clinics, home	 home, hospice facility



“Palliative care is good medical care for patients with serious medical illness.”

- Interdisciplinary care delivery
- Designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering
- Optimizes QOL for patients and families
- Can be delivered at any stage of illness through the collaboration of many types of care providers



Parkinson's Disease

Patients receiving outpatient palliative care experienced:

- Statistically significant benefit in quality of life at 6 months*
- Reduced motor/non-motor symptom burden
- Higher rates of completing advance directives
- Reduced caregiver anxiety at 1 year

JAMA Neurology: Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders: A Randomized Clinical Trial, Benzi M. Kluger, MD1,2; Janis Miyasaki, MD3; Maya Katz, MD4 et al February 2020.

Neuro-Oncology (e.g., Glioblastoma)

Early integration of palliative care significantly improves:

- Psychosocial factors
- Mood
- Patient-reported quality of life compared to standard care alone

Neuro-Oncology: Early palliative care for patients with glioblastoma: A randomized phase III clinical trial (EPCOG), Heidrun Golla et al, January 2026.

Broad Neurodegenerative Conditions (ALS, MS, Dementia)

- A comprehensive review and meta-analysis published in the National Institutes of Health database analyzed 15 trials, (3431 patients)
- Concluding that palliative care consistently improves symptom management and overall satisfaction with care for both patients and informal caregivers across diseases like ALS, Multiple Sclerosis, Parkinson's Disease, Motor Neuron Disease, Multiple System Atrophy, and Progressive Supranuclear Palsy

Effects of Palliative Care for Progressive Neurologic Diseases: A Systematic Review and Meta-Analysis, Lily Man Lee Chan et al JAMDA: 2022.

Palliative Care in Dementia

- Pain management in dementia leads to decrease agitation and behavioral symptoms. *Palliative care and quality of life for people with dementia: medical and psychosocial interventions, Ladislav Volicer et al, International Psychogeriatrics, 2015*
- Integrating palliative care into dementia management helps address unmet needs, provides structured support for family caregivers, and ensures the patient's dignity and care goals are **respected**. *Review Article: Palliative Medicine and Palliative Care for Serious or Advanced Diseases, Elena Gupta, Pragnesh Patel, Annals of Palliative Medicine, 2024*
- Palliative interventions increase the completion of advance directives and formal discussions about goals of care and prevent unwanted, burdensome interventions during the later stages of disease. *Palliative care for people with advanced dementia, Cochrane Review, Walsh et al, 2021*

The Takeaway:

Instead of waiting for the end of life, an "upstream" approach from the time of diagnosis allows care teams to manage complex realities such as grief, functional decline, spiritual distress, advance care planning/preference discussion, symptom management, QOL, and overall patient/caregiver satisfaction.

Trajectories of Illness in Neuropalliative Care

- Patients with Rapid Decline
 - ALS, Brain Tumors, Dementia
 - Quickly changing symptoms
 - Require frequent visits for symptom management
- Patients with Episodic Decline
 - MS, neuroinflammatory conditions, Dementia
 - Requires preference –sensitive decision making
- Patients with Prolonged Decline
 - ALS, Brain Tumors, Dementia, MS, Parkinson's Disease
 - High levels of Caregiver burnout
- Patients with Acute Crisis and Uncertain Recovery
 - Stroke, Traumatic Brain/Spinal Injury
 - Requires preference –sensitive decision making

Unique Aspects of Neuropalliative Care

- Patients with serious neurologic illness may lose their ability to communicate early in their disease course
- Some neurologic diseases are associated with behavioral challenges
- Prognostication is a formidable challenge
- Neurology patients experience their disease as something intrinsic to their person, which clearly differs from patients with cancer who see 'the cancer' as something outside of themselves.
 - Higher degrees of depression, demoralization

Overcoming Challenges

Training Gaps



Missed opportunities for advance Care
Planning discussions



Hospice enrollment in last 7 days of life



Key Palliative Care Opportunities for the Neurologist

- Identifying Patients who need Palliative Care:
 - Surprise question/ ICU Triggers
- Recognizing Serious Illness Conversation Opportunities
 - frequent hospitalizations, unintentional weight loss, cognitive changes, frequent falls, development of serious co-morbidity, change in functional status
- Facilitating Serious Illness Conversations
- Non-neurologic Symptom Management
- Caregiver Assessment
- End of Life Care

Robert Buckman's 6 Point Protocol for Breaking Bad News

- Set the stage
- Patient/family perception
- Invitation
 - Are you ready
 - How much would you like to know?
- Knowledge: educate about the medical situation
- Explore and empathize with emotions
- Summarize the strategy and next steps and decision points.

Non-Neurologic Symptom Management

- Pain
- Dry mouth/Increased Saliva
- Constipation
- Loss of Appetite
- Fatigue
- Insomnia
- Grief
- Depression
- Anxiety
- Spiritual Suffering
- Loss of Dignity
- Depersonalization

Caregivers

Depression is reported in 40 - 60% of caregivers of patients with neurologic conditions.

Caregivers are at higher risk for poor health and mortality compared with age-matched controls.

Risk factors for caregiver burnout include female gender, residing with the patient, financial strain, isolation, low educational level, and obligation as a carer.

Interventions to reduce caregiver burnout may help improve quality of life for patients and allow patients to stay at home longer.



**THANK
YOU**

Any Questions?