Trinity Health

Palliative Care and Compassion

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Disclosures

Nothing to Disclose

Objectives

- List the most common definitions used in the industry
- Review the history of hospice and palliative care
- Identify the Neurologist's role in palliative care
- Discuss how compassion can assist in
  - Prognostication
  - Breaking bad news
  - Hope

IDT Support: Interdisciplinary Team
Best Practice in Hospice and Palliative Medicine

Physicians
Meredith Austin, DO
Alexandra Chis, MD
Linsey Gilbert, MD
Brenda Herrera-Reed, MD
Susan Hickenbottom, MD, MS
Kristen Palomba, MD
Amy Vandenberg, MD

Fellow
Nicholas Gregory, DO

Nurse Practitioners
Dana Berry-Richardson, NP
Mary Beth Maes, NP
Erin Prentice, NP
Nancy Riggs, NP
Naheda Thabata, NP

Social Work
Jennifer Buehrer, LMSW, inpatient
Lindsay Passmore, LMSW, outpatient
Multiple Cancer Center social workers

Inpatient Nurse Team
Donna Fracassi, RN, nurse manager
Liz Beger, RN
Pam Horvath, RN
Chris Ladd, RN
Dana Plater, RN
Emily Sanborn, RN
Kim Stengel, RN

Outpatient Clinic Nurse Team
Natalie Siciliano, RN
Sandy Trembath, RN

Chaplain Support
24/7 Inpatient chaplain services
Chris Hardy, outpatient chaplain for cancer

Scope of Service for Palliative Care

- Palliative care is the comprehensive care and management of the physical, psychological, functional, practical, emotional, and spiritual needs of patients and their families with serious and/or life-threatening illness(es).
- Serious illness is defined as a "health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life or excessively strains their caregiver" (Kelley and Bollens-Lund, 2018).
- Illnesses in this population may include, but are not limited to, chronic and progressive disease such as end-stage organ failure, newly diagnosed or advanced malignancies, and/or sudden and catastrophic such as traumatic brain injury, large hemispheric or brain stem stroke

Definition

Palliative Care actively focuses on relieving suffering and improving quality of life. Care can be offered at the same time as curative or disease-modifying treatment, distinguishing it from hospice care. Palliative care is interdisciplinary and integrates all needed services including pain and other symptom management, psychosocial and spiritual support.

Palliative care is not:

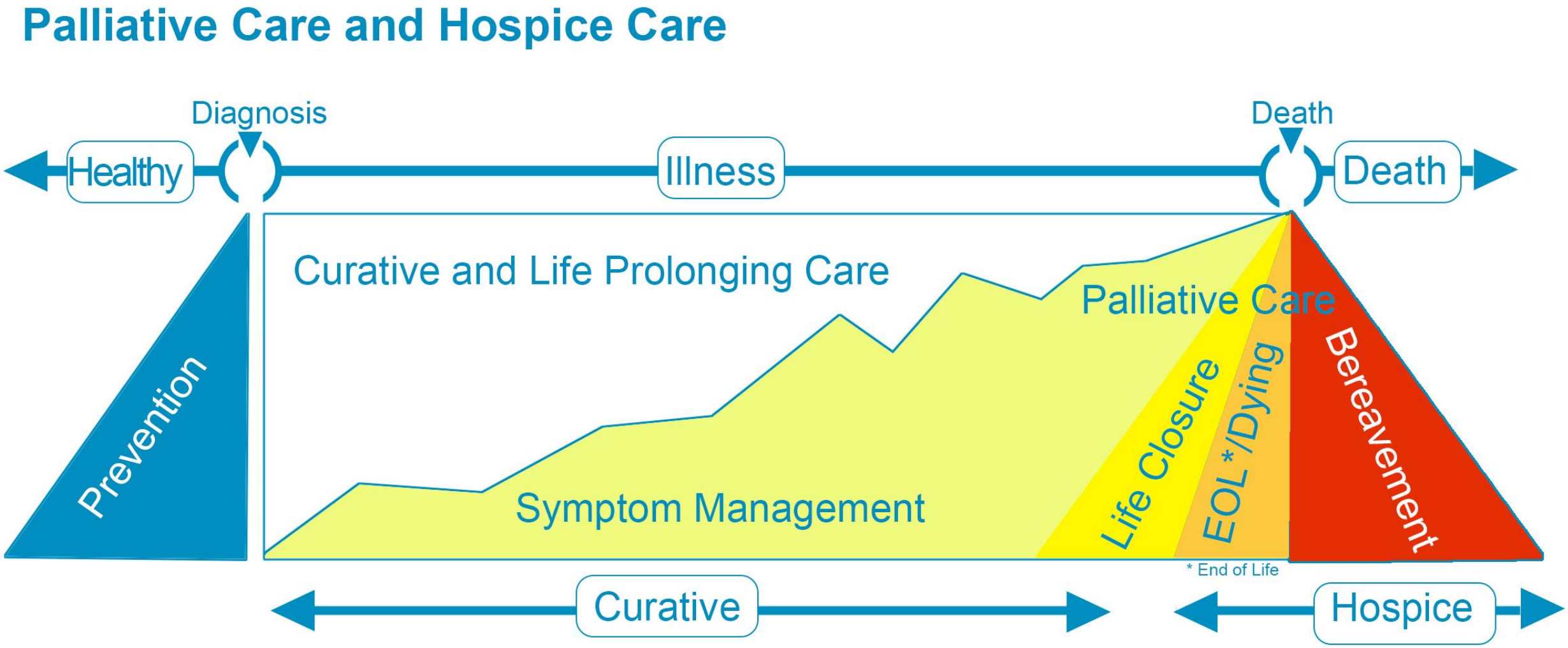
-Status of care

-Hospice

-No care or “giving up”

-The team that will come to make patients/families change their decision

Palliative Care Timeline



https://www.qsource.org/palliative-care/

How Can I Describe Palliative Care to my Patients?

Palliative care is an additional layer of support services that can assist in symptom management, establish and advocate for a patient's desired goals of care and assist with resources to help prevent readmissions

Palliative care is a service that can be made available to every patient with serious illnesses and every patient has the right to learn the role palliative care might play in their treatment

Palliative care is NOT Hospice or End of Life Care – palliative care and assist with both but it is not the PURPOSE or mission of our team

History of Hospice and Palliative Medicine

1948- Dame Cicely Saunders, a nurse in London, was inspired by a patient dying of cancer to start providing what would be known as home hospice care

1967- St. Christopher Hospice of London opened

1980- Medicare mandated hospice care be covered

1990- WHO recognized palliative medicine as a specialty

2006- ABMS and ACGME recognizes Hospice and Palliative Medicine as specialty

Palliative Care Growth

Palliative Care Programs in U.S. hospitals with 50 or more beds, 2000-2020

2000- 24.5%

2012- 69.6%

2020- 83.4%

Neurology Role in Palliative Care

- Fewer than 1% of neurologists are boarded in hospice and palliative medicine (51 in 2016) and about 1-2% of palliative care physicians are neurologists
  - In 2021, subspecialty certification was transferred from ABPN to ABIM
- Palliative care listed as a core competency by ACGME, <52% of neurology residencies had formal lectures on the topic (in 2019)

Despite this, most neurologists already do some palliative care in day-to-day practice

- Serious illness
- Sharing “bad news”
- Pain and symptom management
- Prognostication
- Exploration of patient’s goals and wishes
- Planning for eventual progressive disability and/or end of life

Unique aspects of neurology

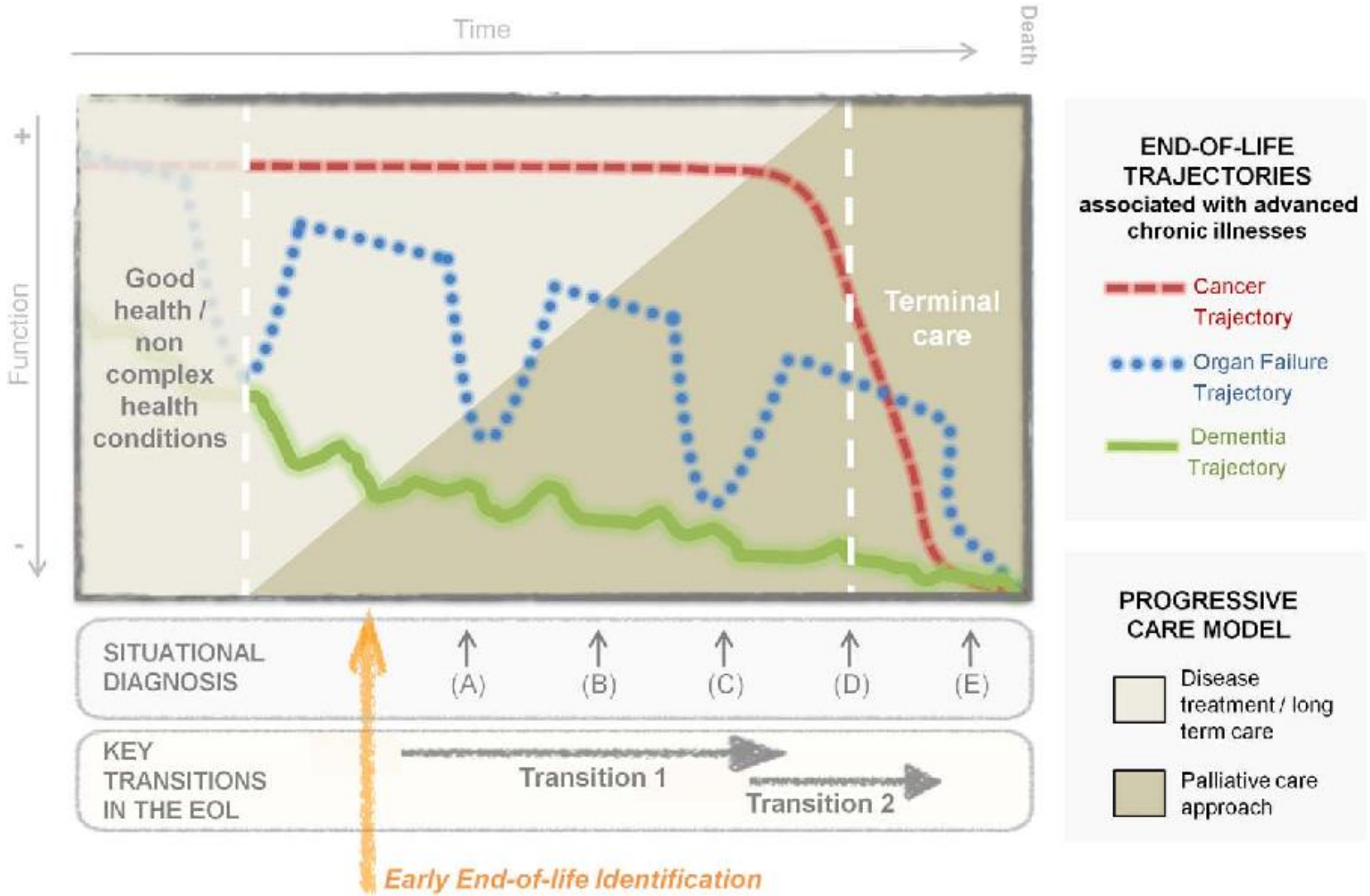
Prolonged and often fluctuating course—unexpected declines and accumulation of impairments

Significant prognostic uncertainty, with few validated predictive markers/models

Loss of mobility, communication and cognitive functioning→decreased ambulatory visits and lost opportunity for advanced planning and end of life decisions

Brizzi and Creutzfeldt “Neuropalliative Care: A Practical Guide for the Neurologist;” *Seminars in Neurology,* 2018 Oct 38(5):569-575

Prognostication



Amblàs-Novellas, Jordi et al. "Identifying patients with advanced chronic conditions for a progressive palliative care approach: a cross-sectional study of prognostic indicators related to end-of-life trajectories." *BMJ Open* 6 (2016): n. pag.

Compassion: Prognostic Uncertainty

Providers to patients and families

- 1) **Normalize uncertainty**→reset expectations
- 2) **Address emotions** about uncertainty→helps respond to emotional distress
- 3) **Manage effect** of uncertainty→ability to live here and now

Provider challenges

- Optimistic bias, overestimate prognosis (5x)
- Unwillingness to talk about this with patients
- More testing to help improve prognostication

Smith AK, White DB, Arnold RM. "Uncertainty—The Other Side of Prognosis." *N Engl J Med* 2013; 368:2448-2450.

Compassion: Prognostic Uncertainty

If there is data, use it as best able

- ICH score, survival/neurologic function after cardiac arrest
- Time from diagnosis to disability/death in neurodegenerative disease

If not, generalized rather than specific

- Hours to days
- Days to weeks
- Weeks to months
- Months to years

Compassion: Breaking Bad News

- Preparing to give bad news
  - Who?
    - Preferably ask the patient
  - What?
    - Review medical information
  - Where?
    - Quiet location, prepare the room
  - When?
    - Time without interruptions

Compassion: Breaking Bad News

- Communicating the bad news—the How
  - Introductions, sit down
  - What does the patient/family know?
  - Warning shot
  - State the bad news directly and succinctly
  - Sit quietly and wait
  - Follow the patient/family lead
  - Be prepared for emotions and validate them
  - Offer to involve others
  - Follow up plan

Compassion: Hope

Conflict between truth telling (providing realistic prognosis) and fear of destroying hope

- Overly optimistic or don't address the information at all
- Intended to protect patients/families (and ourselves) but often counterproductive
- Truth telling ≠ robbing people of hope, nor is our job to "correct" hope

Key question:

Is whether their hope if helping them cope effectively, or whether it is interfering with appropriate behavior and planning

Compassion: Hope

Increase hope:

- Feeling valued
- Having meaningful relationships
- Honesty
- Humor
- Reminiscence
- Pain and symptom relief
- Realistic goals (short, medium, ?long-term)

Destroy hope:

- Abandonment
- Isolation
- Lack of direction or goals
- Unrelieved pain or discomfort
- Feeling devalued or worthless
- Dishonesty

Compassion: Redirecting Goals

What is the patient (and family hoping for)?

Questions to initiate discussion:

- Do you have long term hopes and dreams that have been threatened by this illness?
- I also hope you will improve/disease will stay in remission/etc, but if it doesn't, what other shorter term goals could we work on together?
- What sorts of things do you have that are undone? Let's talk about how we might be able to

Hope for the best but prepare for the worst

Compassion: Imparting Realistic Hope

- Honesty
- Forthrightness
- Confidence
- Good listening skills, maintaining good eye contact
- Calm demeanor
- Ability to allay fears and anxiety
- Compassion

What can Palliative Care do?

Guide

Provide anticipatory guidance

- Make sure pts and families have realistic understanding of what to expect
- Reconcile expectations with care plan and ensure treatment goals are aligned with pt priorities

Coordinate

Provide updates to patient/family in conjunction with primary team

- Arrange and coordinate family meetings
- Support DC planning and outpt referrals by coordinating with CM team

Review

Review code status

Review prognosis

Review plan of care

Review treatment options and goals

Manage

Manage symptoms related to serious life limiting illness

- Pain
- SOB
- Fatigue
- n/v
- Anorexia
- anxiety

Support

Provide ongoing support and coordination of care for primary team, SW, CM, outpatient PCS, etc.

Question or Comments?

To cure sometimes, to relieve often, to comfort always…

Dr. Edward Livingston Trudeau, founder of the Saranac Lake tuberculosis sanitarium