

## Understanding Hospice, Palliative Care and the Evolving Role of End-of-Life Doulas

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## Description and Objectives

This program will review the criteria and benefits of Palliative Care and Hospice. Attendees will learn how early enrollment can benefit patients and their caregivers. The program will conclude with discussion surrounding End of Life Doulas and the positive impact they bring to a hospice program.

### Objectives:

- Review criteria for Palliative Care and Hospice
- Discuss benefits of earlier enrollment in Palliative Care and Hospice
- Describe ethics, trends, scope and role of an End of Life Doula
- Discuss best practices in integrating End of Life Doulas in the patient's advanced illness and end of life journey

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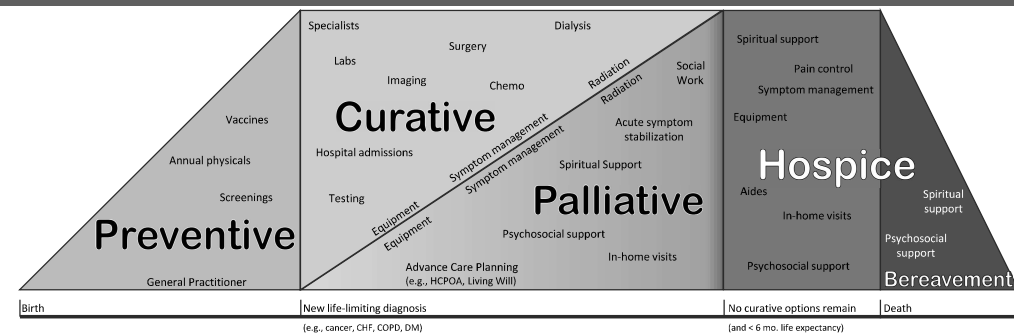
We plan for weddings, the birth of a child, going off to college and retirement.

Despite the conversations we have for these life events, rarely do we have conversations about how we want to be cared for at the end of our lives.



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## Phases of Care: Layers through Life



## Goals of Care Conversations

- Advance care planning conversations
- Complete advance directives
  - Healthcare Power of Attorney
  - Living Will
- Addressing Code Status
  - DNR CC or DNR CC Arrest (Ohio)
- MOLST/POLST (Medical/Physician Orders for Life Sustaining Treatment)

For some patients, avoiding the hospital *is* a goal of care



## Palliative Care

## Palliative Care

- Extra layer of specialized support *in the home* for patients with serious illness
- Team Approach to Care
- Consulting/collaborating with attending doctor to help manage symptoms and goals of care
- Can be utilized in conjunction with skilled services and curative treatments

## Palliative Care Team Approach



### Team includes:

- Nurse Practitioners (NPs)
- RN Coordinators
- Social Worker
- Palliative Physician oversight
- Collaboration with patient's physician

## Unique Aspects of Palliative Care

- Services come to the patient in their “home”
- Nurse Practitioner driven
- Patient’s physician(s) remain part of their care
- Time spent addressing goals of care
- Palliative Care and skilled services or aggressive treatment can be done concurrently

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## Who Can Benefit From Palliative Care

Palliative Care is for anyone living with a serious illness

- Heart failure
- Liver Failure
- Lung Disease
- Kidney Disease
- Neurological conditions (ALS, Parkinsons, Multiple Sclerosis)
- Cancer

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## How Is Palliative Care Covered?

Varies by insurance coverage

- Traditional Medicare – out of pocket cost would be same as a specialist co-pay (covered under Part B)
- Managed Medicare Programs – varies, some require a co-pay, some may cover 100%, may include time constraints
- Private Insurance – varies by plan and provider

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## Transitions to Hospice

- Palliative Care services can help prepare patients for next steps of disease progression
- As patients enter end stage of their disease process, Palliative Care NPs can refer patients to hospice

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# Hospice Care

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## The Hospice Conversation

“It’s a hard conversation to have, enrolling in hospice means that you have to confront that person looking back at you in the mirror and realize that you’re going to die”.

Dr. David Casarett, Professor of Medicine and Section Chief of Palliative Care  
Duke University School of Medicine

New York Times “Here to Help; How Does Hospice Care Work?” March 16, 2023

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## Misunderstanding Hospice Care

- Choosing hospice means you are giving up
  - Choosing hospice is as much about how you want to live as it is about how you want to die
- Choosing hospice means giving up control of your care
  - Patients gain more control when enrolling in hospice care
  - If is not uncommon for patients to begin feeling better once they enroll in hospice care
  - Patients can disenroll from hospice and explore other treatment options.
- My doctor will mention hospice if I need it
  - Doctors often wait for patients to mention hospice
  - Patients/family *can* mention hospice to their doctor
  - Families often state they wish they had understood hospice better and enrolled earlier

*“It’s not about giving up, it’s about speaking up”*

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## When to Consider Hospice

- Diagnosed with a life-limiting illness (such as end-stage heart, lung or renal disease, cancer, dementia, ALS, stroke, neurological disorders, among others)
- Estimated life expectancy of six months or less if the disease follows its natural course; certified by two physicians
- Aggressive procedures/treatments to cure the disease are no longer an option (or desired)

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## "Triggers" to Identify Hospice Appropriate Patients

- Disease is progressing and no longer curable
- Significant weight loss
- Frequent infections
- Frequent ED visits and hospitalizations
- Decline in cognitive abilities
- Decline in function (physical ability, mobility, and independence with ADLs)
- Skin breakdown
- Increased risk factors such as
  - Fall risk
  - Safety risk
  - Aspiration issues
  - Abnormal labs

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## What is Hospice?

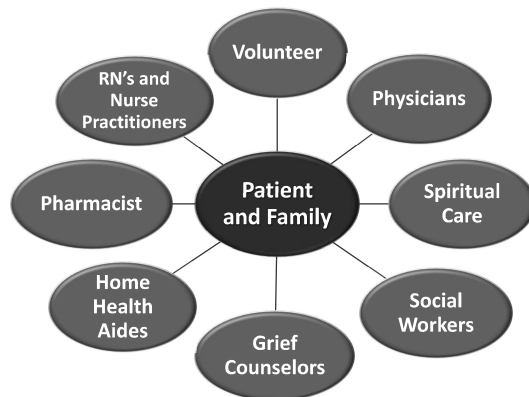
- Hospice is a philosophy of care (*not a place*) provided for patients with an estimated 6- month life expectancy
- Patients must meet criteria to enroll in hospice care
- Hospice is a covered benefit under Medicare Part A, Medicaid and through most private insurance providers
- Hospice benefit covers nursing visits, medications, medical equipment, PT/OT, supplies etc. related to the terminal diagnosis
- Hospice care consists of a team approach to manage the physical, emotional, psychosocial, and spiritual needs



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## Hospice Model of Care: The Interdisciplinary Care Team



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## Goals and Levels of Hospice Care

### Goals:

- Symptom management
- Relieve emotional, psychosocial, spiritual, and physical suffering
- Promote patient and family dignity
- Improve quality of life

### Levels of Care:

- Routine
- General Inpatient (GIP)
- Respite
- Continuous Care

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## When Hospice Care Begins

- Hospice Care begins once patient or HCPOA signs consent forms
- Hospice team coordinates a plan of care at the patient's location of care (includes ordering DME, medications needed, other services needed)
- Utilize evidence-based guidelines for pain and symptom management
- Nursing and Team visits based on patient/family needs
- 24/7 Support



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## Bereavement Care for Families

All hospices are required to provide at least 13 months of bereavement services to family caregivers – this varies by hospice

- Good bereavement care should be comprehensive
- Telephone calls/letters
- Identification of high-risk family members
- Grief Counselors which provide 1:1 services
- Support groups for adults and surviving adolescent children
- Memorial services



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## Hospice Volunteer Doula Program

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## What is an End of Life Doula?

- Simply put “Companion for the Dying”
- Movement
  - Goal is to provide “presence” and companionship
  - Months, Weeks, Days and Hours before death.
- “Presence” takes many forms; non-medical, more holistic
  - Companionship, errands, enrichment, guidance
- Supplemental to medical care, chaplain and social work
- Extra support, attention and time for patient and family

[Article - At the Ready: How Doulas can support Hospices](#)

*Excerpts from NEDA (National End of Life Doula Alliance)*

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## What is Integrative Health?

Holistic approach to Healthcare that combines Conventional and Complementary Therapies

Personalized plan that looks at the whole person including physical, mental, emotional and spiritual well-being.

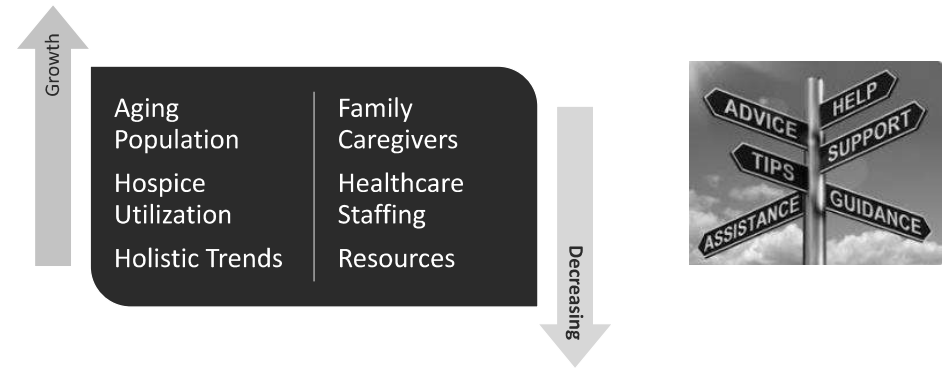
- Person-Centered Care
- Evidence-Based
- CAM Therapies
- Lifestyle modifications

What will support me in living my best life today?  
What is most meaningful to me?  
What stresses me out?  
What relaxes me?  
What brings me joy?



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## Why? – Caregiving Crisis



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## Doula as a Profession

- Certification and Licensure
  - No licensure or certification required in Ohio or US
  - Training programs local and online – INELDA, NEDA, Hospice and DoulaGivers
  - Ethical Standards of Practice
- Models
  - Private Hire by family – bonded and insured
  - Organization – Hourly, patient attendant, Patient Care or Activities Assistant
  - Volunteer – Hospice programs
  - Corporate Retainer – Care Navigation for employees
  - Doula Practice – Birth and End of Life

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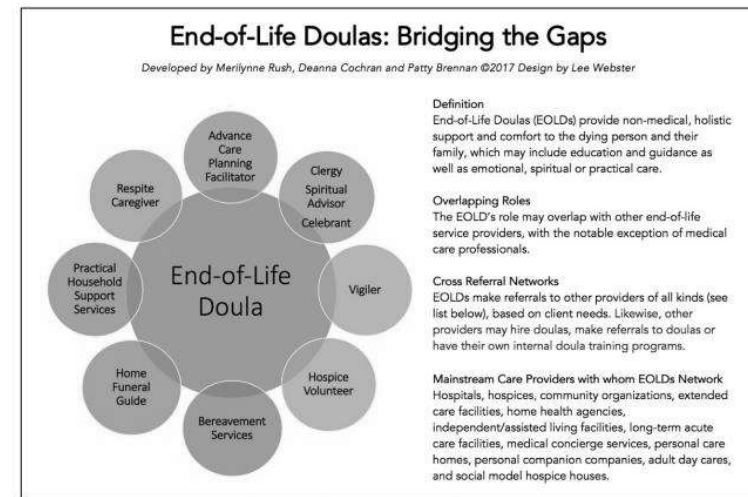


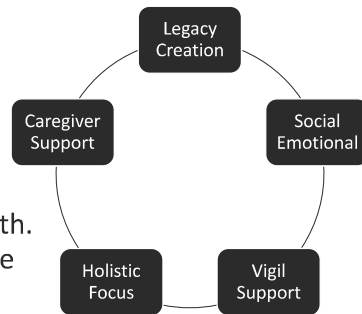
Figure 3: End-of-Life Doulas: Bridging the Gaps<sup>7</sup>

Excerpts from NEDA (National End of Life Doula Alliance)

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## HOC Volunteer Doula Program

- Certification free for HOC Volunteers
- No prior experience or license required
- 1 year cohort
- 100 - hour fellowship
- Cohort Capped at 20 each year
- Applications accepted in February.
- Focused Social, Emotional, Vocational health.
- Follows patient- advanced illness to hospice
- Exam requiring 85% or above to pass
- Monthly networking for regionals Doulas



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## HOC Doula Curriculum

- Hospice and Palliative Care 101
- Admissions and Qualification for services
- Spiritual Care
- Eleventh Hour End of Life care
- Lasting Wish and Legacy
- Teepa Snow Positive Approach Care (PAC)
- Integrative Assessment
- Protecting Quality of Life - "What matters most"
- Access to HOC Caregiver training and education

### Recommended Specializations

- \*Healing Touch and/or Reiki
- \*Guided Imagery and Mindfulness
- \*Music & Memory
- \*Opening Minds through Art (OMTA)
- \*Geriatric Care Manager Certification
- \*Integrative Health Certificate

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Questions?

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## Stories



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## Stories



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## Stories



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## Stories



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THANK YOU

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Guiding you through advanced illness and end of life

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www.hospiceofcincinnati.org