

# Hospice and Palliative Care: What are they?

April 29, 2015



UMASS MEDICAL SCHOOL | COMMONWEALTH MEDICINE  
CENTER FOR DEVELOPMENTAL DISABILITIES EVALUATION AND RESEARCH

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## Welcome and Introduction

- Please use Q&A Box for questions
- [CDDER@umassmed.edu](mailto:CDDER@umassmed.edu) with problems



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## Today's Agenda

- DDS Hospice Use Data
- End-of-life care for people with ID
- Hospice and Palliative Care Overview
- Myths and Misconceptions
- Eligibility and Referral
- Grief and other important considerations
- Case Study
- Questions



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## DDS Hospice Data

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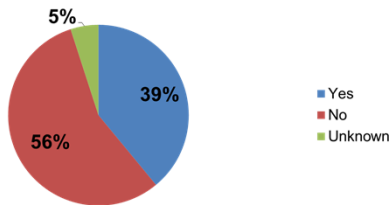
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## Hospice Utilization by DDS Consumers



In 2009, 164 people, or 39% of DDS decedents (people who died), utilized hospice services before their death.



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## Place of death for people using hospice services

- A common goal of hospice is to be able to die at home rather than in a nursing home or hospital.
- In 2009, the majority of people using hospice died at home, and a smaller proportion died in nursing homes or hospitals.
- A larger proportion of DDS consumers using hospice died in their home (76%) than people in the general population (69%) who were using hospice services.

- NHPCO Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, 2010.  
- 2009 DDS Mortality Report



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## End-of-Life Care

- Focuses heavily on quality of life by relieving pain and other distressing symptoms
- Addresses needs of individuals and their family/caregivers/support system
- Tends to the physical and psychosocial needs of the individual

Bekkema, DeVeer, Albers, Hertogh, Onwuteaka-Philipsen, Francke

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## What is Hospice Care?

- A philosophy of approach to care for people who are terminally ill and the medical plan of care is to *maximize comfort and quality of life*.
- Introduced in the U.S. in the 1970s
- The focus is on all aspects of end of life including *physical, emotional and spiritual needs*.
- Alleviates suffering experienced by patients and families during the transitions of a chronic, life limiting illness including *physical suffering, stress, grief, loss of function, loss of identity*.
- Care is delivered by *a team of hospice professionals*.

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## Who is on the Hospice Team?

- Nurse
- Medical Director
- Primary Physician
- Social Worker
- Chaplain
- Volunteers
- Hospice Aides
- Bereavement Counselors
- **Ancillary Services**
  - » Physical Therapy
  - » Occupational Therapy
  - » Speech Therapy
  - » Dietary Counseling
  - » Other Counseling
- **Complementary Therapies**
  - » Music Therapy
  - » Massage Therapy
  - » Art Therapy
  - » Aromatherapy
  - » Pet Therapy
  - » Reiki



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## Offering Care Wherever the Patient Calls “Home”

- Home
- Nursing Home
- Assisted Living Facility
- Group Home
- Hospital
- And, the Kaplan Family Hospice House
  
- **Flexibility in moving from one setting to another**



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## Essential Component of Hospice Care

- Alleviate the suffering of patients and families by focusing on all of its components
  - » Physical, emotional, spiritual and social
- Improving quality of life
- Transitioning patient and families from health to illness to death to bereavement
- Help patients and families in their search for meaning and hope

UNIPAC 2003



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## Some Benefits of Hospice Care

- Hospice team members have expertise in end-of-life care
- Pain and symptoms are managed aggressively
- Caregivers have 24 hours access to the patient’s hospice team
- **Medications and equipment** are covered
- Bereavement support for family and staff

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## Eligibility

- Patient elects to focus on quality of life, symptom control, comfort vs. curative and life prolonging goals
- Patient enrolls in a Medicare-certified hospice program
- Patient's attending physician **and** hospice medical director certify that in their judgment, **given the usual course of the disease**, the patient has a life expectancy of six months or less

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## The Hospice Benefit

- Each patient is allow (2) 90 day benefit periods followed by an unlimited number of 60 day periods
- There is no limit to the number of benefit periods as long as prognosis remains 6 months or less
- Patient can revoke the benefit at any time and return to prior coverage
- Bereavement follow-up 13 months



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## Common Myths and Misconceptions

All hospices are alike or somehow related

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## Reality of Hospice Care

There are many hospice providers available, each offers some differences in the extent of services provided

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## Common Myths and Misconceptions

Hospice is just for Cancer patients

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## Reality of Hospice Care

Primary role is to ease suffering and maintain the dignity of patients – those of all ages, backgrounds, races, diagnoses

- Cardiac Disease
- Respiratory Disease
- Renal Disease
- Liver Disease
- Dementia
- Stroke
- ALS
- HIV

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### Common Myths and Misconceptions

Hospice's involvement in a patient's care leads to a hastening of their death

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### Reality of Hospice Care

Hospice care attempts neither to unnecessarily prolong life nor ever to initiate interventions that hasten the onset of death

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### Common Myths and Misconceptions

Patients can only stay on hospice for 6 months

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## Reality of Hospice Care

Patients are not limited to being on hospice for only six months – in fact, many patients thrive when hospice gets involved

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## Common Myths and Misconceptions

Calling hospice means giving up hope

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## Reality of Hospice Care

Hope may be redefined – for instance, spending more time with family and friends and remaining pain-free

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## When to Consider Hospice/ Who Can Refer

- Support is needed for family and caregivers
- Pain and symptom management is needed for the patient
- The focus of care has shifted from cure to comfort
- **Anyone** can refer – family member, friend, neighbor, doctor, nurse practitioner

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## Grief and People with ID

- Belief that persons with ID do not experience the range of emotions of others including feelings of grief at the loss of family members and close friends/neighbors and, conversely, that they will not be able to “manage” the associated feelings .
- These beliefs and concerns may be used by family members to justify not informing persons with an intellectual disability of the death of parents and for not involving them in funerals and other death and mourning rituals.

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## Grief and People with ID

- Shielding a person with ID from grief/loss can :
  - Cause them to not know how to or have the opportunity to express their grief.
  - Grief does surface. For persons with intellectual disability, later onset and longer duration of grief symptoms are more likely
  - With increased levels of depression, anxiety and distress, grief reactions in persons with intellectual disability are often manifested in behavioral difficulties.
  - These behaviors are more likely to be viewed by family members and professionals as psychosocial concerns rather than as the expression of grief.

McCallion, McCarron, Fahey-McCarthy and Connaire

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## Grief

- Staff in intellectual disability services particularly prone to grief.
- There is also grief for the other persons with intellectual disability in the home and for the family

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## Definition

### Palliative Care

“An approach that improves the quality of life of patients and their families, facing the problems associated with life threatening illness, through the prevention and relief of suffering, by means of early identification, impeccable assessment, treatment of pain and other problems physical, psychosocial, and spiritual.”

(Sepulveda et al.,2002; World Health Organization, 2002)

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## Who Can Receive Palliative Care?

A palliative care consultation is appropriate for any patient with a chronic or progressive, life-limiting illness, even those receiving curative treatment.



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## Palliative and Hospice Care Similarities

- Focus on comfort through aggressive pain and symptom management
- Goal is quality of life
- Educates and supports patients, families, caregiver, and medical team
- Addresses physical, psychosocial, spiritual, and social needs
- Provided in a variety of settings (home, hospital, ALF's, nursing facilities, etc...)

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## Differences

### Palliative Care

- Can receive/pursue curative, disease modifying or life prolonging treatment
- Eligibility not based on life expectancy
- Consultative in nature
- Covered under Medicare B and most private insurances
- Helps to clarify goals of care together with family and medical team

### Hospice Care

- Comfort-based rather than curative
- Eligibility guidelines set by Medicare based on prognosis of 6 month or less
- Eligible individuals sign onto hospice benefit
- Covered under Medicare A benefit, Medicaid and most private insurance
- Intensive interdisciplinary support for patient and family

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## The Referral Process

- **Physicians must request a consult**
- **Recommendations:** Recommendations will be shared with the Primary Care provider and/or referral source
- **Follow-up:** Arranged as needed

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### Best Practices for Care Collaboration

- Need for staff in ID setting to understand Hospice/Palliative Care
- Need for Hospice/Palliative Care staff to understand the care needs of people with ID
- Need for increased literature on Hospice/Palliative Care needs of people with ID
- Collaboration between ID staff and Hospice/Palliative Care staff - this improves care and provides a greater exchange of expertise

McCallion, McCarron, Fahey-McCarthy and Connaire

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### Case Study

- Peter lived independently in the community
- His sisters were his guardians
- Peter had Down Syndrome and Alzheimer's
- Functioning declined and he moved into a DDS group home
- After about a year and a half he qualified for hospice care

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### Case Study

- Group Home and hospice staff successfully partnered to provide end-of-life care
- Peter successfully died at home
- Housemates and staff received support with grieving

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## Resources/Materials

1. *Supporting Persons with Intellectual Disability and Advanced Dementia: Fusing the Horizons of Intellectual Disability, Dementia and Palliative Care: A training Curriculum.*

2. End of Life Care: A guide for supporting older person with intellectual disabilities and their families.

[http://www.nysarc.org/files/3213/0995/7606/Advocacy\\_Monograph\\_No.\\_3\\_2.22.11.pdf](http://www.nysarc.org/files/3213/0995/7606/Advocacy_Monograph_No._3_2.22.11.pdf)

3. <http://ddhospiceandpalliativecare.org/>

McCallion, McCarron, Fahey-McCarthy and Connaire

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## DDS Resources

• Quality Is No Accident – Alzheimer's' and Dementia

<http://www.mass.gov/eohhs/docs/dmr/reports/qa-gina-alzheimer-dementia.rtf>



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## Resources

• National Hospice & Palliative Care Organization

[www.nhpco.org](http://www.nhpco.org)

• Hospice & Palliative Care Federation of Mass.

[www.hospicefed.org](http://www.hospicefed.org)



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- McCallion, Philip, McCarron, Mary, Fahey-McCarthy, Elizabeth and Connaire- Kevin , Meeting the End of Life Needs of Older Adults with Intellectual Disabilities

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## Contact Information

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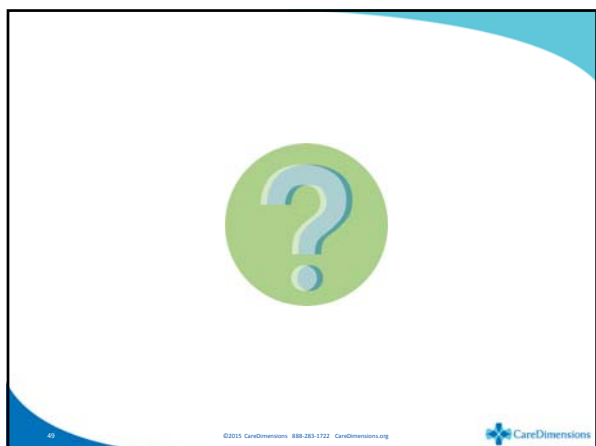
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