

Palliative and Hospice Care for Persons with Disabilities

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March 7, 2018

The 2018 Disability-Competent Care Webinar Series: Palliative and Hospice Care for Persons with Disabilities



Webinar Overview

- The Lewin Group, under contract with the CMS Medicare-Medicaid Coordination Office, partnered with Christopher Duff and other disability practice experts to develop the 2018 Disability-Competent Care webinar series. This is the third webinar in the series.
- This webinar series builds on the 2017 Disability-Competent Care webinar series, that introduced the model of care and its seven foundational pillars. To view this series, please visit:
https://www.resourcesforintegratedcare.com/DisabilityCompetentCare/2017_DCC_Webinar_Series/Series_Overview
- Each session will be interactive (e.g., polls and interactive chat functions), with 45 minutes of presenter-led discussion, followed by 15 minutes of presenter and participant discussions.
- Video replay and slide presentation are available after each session at:
<https://www.resourcesforintegratedcare.com>

Continuing Education Accreditation

- The Centers for Medicare & Medicaid Services is accredited by the International Association for Continuing Education and Training (IACET) for Continuing Education Units (CEU) and by the Accreditation Council for Continuing Medical Education (ACCME) for Continuing Medical Education (CME, AMA PRA Category 1 credit for physicians and non-physicians).

Obtaining Continuing Education Credit

- Complete the post-test through CMS' Learning Management System and score a 80 percent or higher by midnight March 26, 2018.
- https://resourcesforintegratedcare.com/sites/default/files/DC_CWebinar3_CMSCEGuide_PreWebinar.pdf

Support Statement

- This webinar is supported through the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to dually eligible beneficiaries, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar.
- To learn more about current efforts and resources, visit Resources for Integrated Care at:
<https://www.resourcesforintegratedcare.com>

Introductions



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Webinar Learning Objectives

This webinar will emphasize:

- The fundamentals of providing palliative care and hospice care, including what differentiates the two
- Historical background to understand fears about palliative and hospice care within the disability community
- Techniques for discussing palliative care options with participants and their families

Agenda

- Understanding palliative care and hospice care
- Fears of palliative and hospice care within the disability community
- Providing hospice care
- Care Oregon's palliative care programs
- Audience questions

Understanding Palliative Care and Hospice Care



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National Hospice and Palliative Care Organization



What is Hospice Care?

- Hospice provides support and care for participants and their families in the last phases of life-limiting illnesses.
 - Recognizes dying as part of the normal process of living
 - Affirms life and does not hasten or postpone death
 - Focuses on quality of life for participants and their families
 - Promotes a caring community that is sensitive to participant needs
 - Aims to provide participants and their families some degree of satisfaction in the preparation for death
 - Offers palliative care throughout the dying process

What is Palliative Care?

- Palliative care is specialized medical care that is used by people living with serious illness.
 - It focuses on providing relief from illness symptoms and stresses. The goal is to improve quality of life for both the participant and their family.
- Palliative care is provided by a team of doctors, nurses, social workers, and other providers.
 - Together this group works with care specialists to provide additional support.
- Palliative care is appropriate at any age and at any stage of a serious illness. It can be provided along with curative treatment.

Palliative Care vs. Hospice Care

Palliative Care

- Focuses on relief from physical suffering. The participant may or may not be terminally ill.
- Addresses the participant's physical, mental, social, and spiritual well-being; is appropriate for participants in all stages of a disease; accompanies the participant from diagnosis to cure.
- Uses life-prolonging medications.
- Can be offered where the participant first sought treatment.

Hospice Care

- Available to terminally ill participants.
- Focuses on making the participant comfortable for end of life.
- Does not use life-prolonging medications.
- Offered at a place the participant prefers, e.g., their home, a nursing home, or a hospital.

Dually Eligible Beneficiaries

- Both Medicare and Medicaid provide hospice coverage for Medicare-Medicaid enrollees. Which program covers what, when, and under what circumstances may be complicated and confusing for providers, beneficiaries, and payers.
- For palliative care services, benefits and payers can vary state-to-state.

Fears of Palliative and Hospice Care within the Disability Community



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Brief History of the Treatment of Persons with Disabilities

- In the 1800s, some individuals with disabilities (both mental and physical) were labeled as “deviant” and housed in asylums.
- Around the world, a movement for disability rights evolved that demanded inclusion for people with disabilities.
- In the 1970’s, the disability community lobbied the federal government for independent living rights, advocating for legislation concerning those living with debilitating ailments. Their efforts, with the help of the Civil Rights movement, led to the Rehabilitation Act of 1973.
- This was followed by the Individuals with Disabilities Education Act of 1975 and most notably, the Americans with Disabilities Act of 1990.

Fears of Palliative and Hospice Care in the Disability Community

- There are many stories of persons with severe disabilities (or their families) being told they would remain vegetative or never regain functional ability. Yet, over time, many progressed to lead meaningful lives.
- For those with long-term disabilities, many have been given the impression that they are of lesser value. A common mantra has emerged among participants: “Not Dead Yet.”
- This history of medical professionals and the industry as a whole viewing persons with disabilities through the lens of a diagnosis or ‘broken body’ has led to distrust on the part of persons with disabilities, and adds a greater challenge to discussions of advance directives, palliative care, or hospice.

Having the End-of-Life discussion

- Evaluating and determining “quality of life” is a delicate topic, one that can be emotionally charged within the disability community, as it can be heard as “ending life”.
- Many hospice providers are aware of person-centered care, but culturally ingrained prejudices can persist. Most of the experience hospice providers have with disabilities are those that are brought on through the progression of a terminal illness - which can be a very different experience compared to a life-long disability.
- Many experienced practitioners have found it is best to initiate discussions of palliative and hospice care within an existing, trusting relationship, such with a care coordinator or primary care provider.

Providing Hospice Care



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Beneficiaries Using Hospice

- In 2016, 1.4 million Medicare beneficiaries used hospice care. Compared to beneficiaries on Medicare alone, dually eligible beneficiaries are more likely to use hospice services.
- Beneficiaries using hospice care have a range of diagnoses and conditions:
 - Cancer – 27.7%
 - Cardiac and circulatory – 19.3%
 - Dementia – 16.5%
 - Respiratory – 10.9%
 - Stroke – 8.8%
 - Other – 16.7%

Source: 2) NHPCO Regulatory Alerts; April 25, 2016.

Levels of Hospice Care

The level of hospice care is determined by the participant's needs. Beneficiaries who elect hospice care can receive services through Medicare-certified hospice providers. The vast majority of hospice care provided under Medicare is for services in the participant's residence:

- Routine home care (97.8% of services)
- Continuous home care (0.3% of services)
- Inpatient (0.3% of services)
- Respite (1.6% of services)

Source: 3) NHPCO: Facts and Figures; Hospice Care in America. 2016 Edition

Referral to Hospice Care

1. Participants obtain a physician's note indicating a life-limiting illness with a prognosis of six months or less if the disease takes its normal course. Critical to this step is separating the participant's disability from their terminal state. An established, trusting relationship with a care coordinator and primary care provider can help.
2. A hospice physician is identified. Alternatively, the participant may choose their primary care provider for hospice care.
3. A nurse and other interdisciplinary team (IDT) members complete an initial, comprehensive assessment.
4. The overseeing physician develops a hospice care plan.
 - The hospice care plan determines what disciplines should be added to the IDT to provide appropriate care and support.

Roles within the IDT

The hospice IDT may include many people with different functions, including:

- Allied therapy professionals: physical, occupational, and speech therapy
- Chaplains
- Complementary therapists: massage, art, or music
- Counselors, including dietary or bereavement
- Certified nurse assistants or hospice aides
- Nurses
- Physicians
- Social workers
- Volunteers, as available through the hospice program
- In-home para-professional care

Role of the IDT in Hospice

In hospice care, the IDT:

- Manages participant pain and symptoms
- Assists the participant, their family and care partners with the emotional, psychosocial, and spiritual aspects of dying
- Provides required medicine, medical supplies, and equipment
- Instructs the family and other care partners on how to support the participant through their dying process
- Delivers special services (e.g., respiratory and physical therapy)
- Makes short-term inpatient care available when pain or symptoms become too difficult to treat at home or when the care partner needs respite
- Provides bereavement care and counseling to surviving family, care partners and friends
- Coordinate with in-home personal care services

Providing Hospice Services to Individuals with Disabilities

- Providers initiating the conversation around hospice care with individuals with disabilities should be sensitive to their history.
 - Acceptance of the end-stage of life may be more challenging for individuals with life-long disabilities as they may have faced difficult health crises in the past.
- Hospice providers should not assume participants need or want help with certain tasks, as many persons with disabilities want to be treated as independent.
- Hospice providers should be sensitive about physical contact:
 - Avoid touching an individual's wheelchair, scooter, or cane, as their equipment is part of their personal space.

CareOregon's Palliative Care Programs



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CareOregon

- CareOregon is a non-profit health plan that has focused on services, reforms, and innovations since 1994.
 - Serves Oregon Health Plan (Medicaid), Medicare, and dually eligible members.
 - Provides health plan services to four coordinated care organizations, serving approximately 250,000 Oregonians, and about 11,000 dually eligible beneficiaries.
 - Members receive care in community health centers, large health systems, academic health centers, private practice groups, and hospital-affiliated group practices.
- Our mission is cultivating individual well-being and community health through shared learning and innovation.
- Our vision is healthy communities for all individuals, regardless of income or social circumstances.

Participant Experience: Paul

- Paul is a 50 year old dually eligible beneficiary with metastatic cancer and a long history of behavioral health issues leading to multiple chronic health conditions. He has been on public programs for most of his adult life.
- His recent job loss, addiction issues, divorce, and estrangement from his children contributed to his social isolation. As Paul described it, his life became a slow motion, downward spiral which he could never quite get under control.
- Through the process of diagnoses and treatment, he left the hospital several times “against medical advice.” Following aggressive treatment, Paul rejected hospice care as “giving up” but accepted there was no further curative therapy available.
- As with many individuals with disabilities and those relying on public programs, Paul expressed fear of losing his independence and was resistant to discussing hospice or palliative care options.

Understanding the Participant

A participant is more than their diagnosis, and it's important to also consider past history and experiences.

- Research has shown that a history of trauma and household dysfunction can have lasting health affects throughout life.⁴
- Individuals on public programs, especially those who are dually eligible beneficiaries, are particularly susceptible to the conditions that lead to increased health disparities.
- Several recent studies have also shown the correlation between social determinants of health and chronic illness and disabilities.^{5,6}

Source: 4) Felitty et al. American Journal of Preventive Medicine; 1998.

5) Office of the Assistant Secretary for Planning and Evaluation. (2016). Report to Congress

6) Disability and Health. Healthy People 2020.

Recognizing Past Experiences

- CareOregon recognized that past experiences should inform services for dually eligible and Medicaid beneficiaries, which led to the development of the Health Resilience Program (HRP).
- HRP is a care management approach for participants with complex health needs that takes into account life history and past trauma, including fears that can be associated with hospice and palliative care.
- Knowing the participant's history and current abilities helps to inform the nature, type, and amount of services needed.

Source: 4) Felitty et al. American Journal of Preventive Medicine; 1998.

5) Office of the Assistant Secretary for Planning and Evaluation. (2016). Report to Congress

6) Disability and Health. Healthy People 2020.

Care Management Approach

- CareOregon's care management approach focuses on understanding the participant's experiences and their health goals.
- Often, a participant may not be willing to follow their provider's treatment plan. Faced with this, CareOregon's approach includes listening to their fears, and looking at the treatment plan from the participant's perspective.
 - E.g. "What do you understand about the plan?"

CareOregon's Palliative Care Population

- CareOregon used demographic data early in their program to better understand members receiving palliative care.

Age Range	Members
65 and older	37%
60 - 64	17%
55 - 59	20%
50 - 54	10%
Under 50	16%

Unique Member Needs

- Dually eligible adults younger than 65 have significant health problems and report more barriers to health care access than dually eligible adults 65 or older.⁷ Barriers may include the lack of availability and access to:
 - Community-based services
 - Housing
 - Transportation

Source: 7) SAMHSA: The CBHSQ Report; July 15 2014.

Traditional vs. Safety-Net Palliative Care

- Traditional palliative care services:
 - Focus on symptom management through primary care providers or palliative care specialists
- Safety-net palliative care services:
 - Offer additional supports to meet participant's socioeconomic (e.g. housing and transportation) and behavioral health needs
 - Support the building of relationships during the care process for participants, providers, and care partners
 - Account for and recognize participant's lived experience with disability, including access to care and services, socioeconomic challenges, and social participation.

CareOregon's Palliative Care Programs

Safety-net palliative care services are offered through the:

- **Advanced Illness Care Program**
 - Primary and specialty care is provided by community-based practitioners, outside the home.
 - The CareOregon IDT “wraps around” and supports the community provider.
 - The IDT includes registered nurses, social workers, and outreach works, and support from a chaplain and pharmacy.

- **Housecall Providers**
 - Palliative care delivered through a home-based primary care team.
 - Participants have a primary care provider who is integrated within Housecall Provider's IDT.
 - The IDT includes registered nurses, social workers, and outreach workers, and support from a chaplain and pharmacy.

Finding the Best Program for Participants

- Participants are introduced to these programs and encouraged to choose which services best suit their needs.
- The Advanced Illness Program is introduced to the participant as a triad of services:
 - Care coordination
 - Identifying care goals
 - Managing symptoms
- The Housecall Providers Program is introduced to participants in a way that will help mitigate program fears:
 - “Imagine a service that brings nurses, social workers, chaplains, and aides to your home to make sure your quality of life is as good as possible.”
 - “They work with your doctor, too. How does this sound?”
 - “This service is called palliative care. If you are wanting to focus on quality of life, this could be an option for you.”

Palliative Care Program Successes

- Effective palliative care improves the quality of life by focusing on social determinants of health and developing provider and care partner relationships.
- Strong relationships within the care team enable important and difficult conversations around hospice and palliative care, particularly for those with disabilities.
- Integrating community-based services: CareOregon is partnering with a local housing and health care organization to open a 10-bed inpatient care unit in early 2019.

Participant Experience: Paul

- Although Paul refused hospice care, the care team understood his resistance and continued to engage him with care options that could meet his needs as they continue to work with him.
- Paul's medical treatment was complicated due to his disabilities and behavioral health issues; however the relationships built through the palliative care services offered crucial support.
- Through the coaching and support of his palliative care team, he was able to reconcile with his family before he died. He passed away peacefully at a family member's home.
- Before passing away, Paul said to a member of his palliative care team: "I used to be falling, now I am not."

Concluding Thoughts

- Participants with disabilities who face challenges related to social determinants of health may require a tailored approach to palliative care services.
 - Focus on relationship building to facilitate effective communication around difficult topics.
 - Offer staff development and support related to building relationships with participants to better understand the lived experience of disability and participants' past experiences.
 - Partner with external providers for complementary services.

Audience Questions



Next Webinar

Supporting Participants with Complex Behavioral Health Needs

Date: March 14th, 2018

Time: 2:00pm – 3:00pm ET

Thank You for Attending!

- The video replay, slide presentation, and a summary of the Q&A will be available at:

<https://www.resourcesforintegratedcare.com>

- For more information about obtaining CEUs or CMEs via CMS' Learning Management System, please visit:
https://resourcesforintegratedcare.com/sites/default/files/DC_CWebinar3_CMSCEGuide_PreWebinar.pdf
- Questions? Please email RIC@lewin.com

Webinar Evaluation Form

- Your feedback is very important! Please take a moment to complete a brief evaluation on the quality of the webinar. The survey will automatically appear on the screen approximately a minute after the conclusion of the presentation.

Send Us Your Feedback

Help us diversify our series content and address current Disability-Competent Care training needs – your input is essential!

Please contact us with your suggestions at

RIC@Lewin.com

What We'd Like from You:

- How best to target future Disability-Competent Care webinars to health care providers and plans involved in all levels of the health care delivery process
- Feedback on these topics as well as ideas for other topics to explore in webinars and additional resources related to Disability-Competent Care

Sources

1. Centers for Medicare & Medicaid Services: Palliative Care vs. Hospice Care; Similar but Different.
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6. Disability and Health. Healthy People 2020.
 - <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health/ebrs>
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 - <https://www.samhsa.gov/data/sites/default/files/SR180/sr180-dual-eligibles-2014.pdf>

Resources

- National Hospice and Palliative Care Organization
 - <https://www.nhpc.org/explanation-palliative-care>
- Center for Advanced Palliative Care
 - <https://www.capc.org/about/capc>
- Advanced Care Planning Videos
 - <https://www.acpdecisions.org/products/videos>
- Participant and Provider Videos on advanced care planning decisions
 - <https://www.acpdecisions.org>