PROJECT ECHO MINISERIES:

BEST PRACTICES IN DEMENTIA CARE

Hosted in collaboration with the
Alzheimer's Association

Seven weekly sessions
Thursday, 3 – 4 p.m. ET | March 7 – April 18

nhpco.org/projectecho

NHPCO

Assessment and Care Planning

March 14, 2024

Disclosures

Disclosure

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

Please complete program evaluation materials following each session.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Today's Agenda

- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

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Didactic Presentation

Learning Objectives

After today's didactic, you will be able to:

- Describe the components of regular, comprehensive person-centered assessments.
- Describe the importance of advance care planning.

DCPR Recommendations

- Perform regular, comprehensive person-centered assessments and timely interim assessments
- Use assessment as an opportunity for information gathering, relationship-building, education, and support
- Approach assessment and care planning with a collaborative, team approach
- Use documentation and communication systems to facilitate the delivery of person-centered information between all care providers
- Encourage advance planning to optimize physical, psychosocial, and fiscal wellbeing and to increase awareness of all care options, including palliative care and hospice

Comprehensive PCC Assessment

Experience of the person/care partner

Function and Behavior

Health Status and Risk Reduction

Purpose of Assessment

- Identify strengths or areas of opportunity to enhance the individual's ability to live fully and meaningfully.
- Identify issues that detract from the individual's ability to live fully and meaningfully.
- Opportunity for relationship-building, therapeutic partnership, education and support.
- Provide an environment where a person can function with minimal failure and maximal use of retained abilities!

Assessment Content

- Strengths
- Challenges and unmet needs
- Learning “what matters” - individualized approaches focused on the individual’s experience, the family member’s experience and the direct caregiver’s experience
- Evidence-based approaches using reliable and valid assessment tools: clinical status, symptoms, cognition, behavior, function
- Identification of risks and conditions to be addressed in the care plan

Team-Based Approach

- Team members:
- Person living with dementia
- Care partners and caregivers
- Direct care providers
- Family
- Primary care providers
- Interdisciplinary health care team
- SW, OT, PT, SLP, Dietician, Pharmacist
- Coordinator or care manager

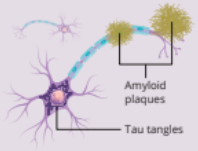
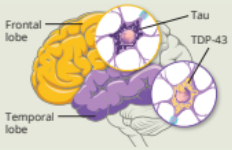
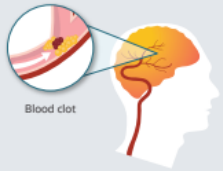
Documentation & Communication

- Comprehensive, high-quality assessment is of benefit only if it is documented and shared with care providers for use in planning and evaluating care.
- Information must be current, accessible, and utilized.

Encourage Advance Planning

- **Early and ongoing discussion about what matters**, including values, quality of life and goals for care.
- Refer to healthcare team members to provide ongoing education and support about symptom management and palliative care.

TYPES OF DEMENTIA

Alzheimer's Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
What Is Happening in the Brain?*			
g) is signed in deposits of proteins form amyloid plaques and tau tangles throughout the brain. 	Abnormal amounts or forms of tau and TDP-43 proteins accumulate inside neurons in the frontal and temporal lobes. 	Abnormal deposits of the alpha-synuclein protein, called "Lewy bodies," affect the brain's chemical messengers. 	Conditions, such as blood clots, disrupt blood flow in the brain. 
*These changes are just one piece of a complex puzzle that scientists are studying to understand the underlying causes of these forms of dementia and others.			
Symptoms			
Mild • Wandering and getting lost • Repeating questions **Moderate** • Problems recognizing friends and family • Impulsive behavior **Severe** • Cannot communicate	**Behavioral and Emotional** • Difficulty planning and organizing • Impulsive behaviors • Emotional flatness or excessive emotions **Movement Problems** • Shaky hands • Problems with balance and walking **Language Problems** • Difficulty making or understanding speech *There are several types of frontotemporal disorders, and symptoms can vary by type.*	**Cognitive Decline** • Inability to concentrate, pay attention, or stay alert • Disorganized or illogical ideas **Movement Problems** • Muscle rigidity • Loss of coordination • Reduced facial expression **Sleep Disorders** • Insomnia • Excessive daytime sleepiness **Visual Hallucinations**	• Forgetting current or past events • Misplacing items • Trouble following instructions or learning new information • Hallucinations or delusions • Poor judgment
Typical Age of Diagnosis			
Mid 60s and above, with some cases in mid-30s to 60s	Between 45 and 64	50 or older	Over 65

Diagnosis

Symptoms can be similar among different types of dementia, and some people have more than one form of dementia, which can make an accurate diagnosis difficult. Symptoms can also vary from person to person. Doctors may ask for a medical history, complete a physical exam, and order neurological and laboratory tests to help diagnose dementia.

Treatment

There is currently no cure for these types of dementia, but some treatments are available. Speak with your doctor to find out what might work best for you.

Living with dementia can be challenging, but there are ways to manage it. To learn more about these types of dementia and other conditions that can cause dementia, visit **www.nia.nih.gov/health/what-is-dementia**.

NIH National Institute on Aging

ALZHEIMER'S ASSOCIATION

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Hospice LCDs

Hospice Determining Terminal Status L34538

CMS Local Coverage Determination for Alzheimer's Disease and Related Disorders:

- Fast score: stage 7 or beyond
- One of the following within the past 12 months:
  - Aspiration pneumonia
  - Pyelonephritis or other upper urinary tract infection
  - Septicemia
  - Decubitus ulcers, multiple, stage 3-4
  - Fever, recurrent after antibiotics
  - Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous six months or serum albumin <2.5 gm/dl

cms.gov/medicare-coverage-database

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Hospice LCDs

Hospice Alzheimer's Disease & Related Disorders L34567

- Fast score : stage 7 or beyond
  - Stage #7: Loss of speech, locomotion, and consciousness:
    - Sub-stage 7a: Ability to speak limited (1 to 5 words a day)
    - Sub-stage 7b: All intelligible vocabulary lost
    - Sub-stage 7c: Non-ambulatory
    - Sub-stage 7d: Unable to sit up independently
    - Sub-stage 7e: Unable to smile
    - Sub-stage 7f: Unable to hold head up
- Comorbid Conditions
  - The significance of a given comorbid condition is best described by defining the structural/functional impairments, together with any limitation in activity, related to the comorbid condition.
- Secondary Conditions
  - The significance of a given secondary condition is best described by defining the structural/functional impairments, together with any limitation in activity, related to the secondary condition.

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Didactic Presentation Q&A

Case Study Presentation:
End-stage Dementia Review of Eligibility

Situation

- This patient is an 89-year-old with a hospice diagnosis of Alzheimer's disease with dementia. The patient lives with their daughter who serves as the patient's health care proxy, son-in-law, and adult grandchildren, who are the patient's caregivers.
- The patient is being evaluated for ongoing hospice eligibility.

Background

- This patient is entering their seventh benefit period.
- FAST score is 7F, unchanged from the previous benefit period.
- The patient is well cared for by their family, who provide around the clock total care for the patient who can no longer make their needs known.
  - In this, the patient's family is guided by previous discussions with the patient in terms of what is important to them and how they want to be cared for.
  - The patient's family has shared reminiscences and photos of the patient before they reached end stage dementia so that the team could better understand how robust the patient was prior to the progression of disease and the context in which the patient is viewed by their family.

Assessment

- The patient is assessed by the team and found to have no significant changes over the past benefit period.

Discussion and Recommendations

Discussion and Recommendations

- This patient is cared for by family members. The patient has “mixed incontinence” and is tolerating their diet without signs or symptoms of aspiration.
- The patient requires assistance in all activities of daily living, including needs to be fed.
- The patient’s family notes decreased oral intake.
- The patient has had a slight drop in arm circumference.
- The patient spends most of the day sleeping in bed.

- This patient is cared for meticulously by their family caregivers who toilet the patient at regular intervals, and who carefully hand feed the patient a diet of pureed foods and thickened liquids.
- Over the course of the past benefit period, the patient has required longer feeding times, now extended to between 60 and 75 minutes, previously taking 30 to 45 minutes.
- The patient is noted to be accepting less food over the course of a day, taking in 8 ounces per day, previously taking in up to 12 ounces per day.
- The patient is unable to stand to be weighed and upper arm circumference measures have continued to drop, having dropped another 0.5 cm over the course of the past benefit period.
- The patient is noted to have increased somnolence, now sleeping 22 hours per day, previously sleeping 18 hours per day.
- The patient no longer acknowledges the hospice chaplain when prayers are said.

Discussion and Recommendations

This patient is an 89-year-old with a hospice diagnosis of Alzheimer's disease. The patient has end stage disease as evidenced by a FAST score of 7F as he is non-verbal, bed bound, lacking the ability to support his trunk or head, and no longer smiles. This progression from a FAST score of 7E to 7F has occurred over the past five months. The patient is noted to have worsening contractures of the lower extremities. His appetite is poor, and his family notes a decrease in appetite in recent months. Over the course of a day, the patient will take in 1/2 cup of fluids, cumulatively, compared to previous intake of up to 1 full cup of fluids. The patient is taking in only 6 tablespoons of pureed foods at each meal, three times a day. The patient is on a modified diet of pureed foods due to dysphagia. The patient has noted visual signs of weight loss as evidenced by cachexia, bitemporal wasting, and sunken orbits with protruding cheekbones. The patient requires complete assistance in all activities of daily living, including feeding. PPS is 30%.

This patient is an 89-year-old with a hospice diagnosis of Alzheimer's disease. The patient is at the very end stage of disease as evidenced by a FAST score of 7F that finds the patient non-verbal, bed bound, unable to smile, and lacking trunk and head control, as the patient is not able to hold up is own head. The patient is cared for meticulously through teaching to his family. He requires complete assistance with all activities of daily living and personal care. This includes feeding, which is 1:1 careful feeding provided by his family with the patient taking in less than 6 tablespoons of pureed food at most up to three times a day. In the course of a day the patient will take in at most 1/2 cup of fluids in total although it is reported that the patient is often not taking in even that much, most days taking in only two such meals. Due to dysphagia the patient requires a modified diet of pureed foods. The patient has an area of non-healing skin breakdown at the ankle, which persists. The patient's lower extremities are severely contracted with visible signs of muscle wasting and worsening contractures of the lower extremities. He has a cachectic appearance with a persistent downward trend in arm circumference, decreased between 4 and 5 cm over the past seven months (between March and October) to arrive at a MUAC of 17.8 cm. PPS is reported as 30%.

Discussion and Recommendations

This patient is an 89-year-old with a hospice diagnosis of Alzheimer's disease. The patient is at end stage disease as he is bed bound, non-verbal, unable to smile, and lacking truncal and head support. His FAST score is 7F. The patient has had ongoing weight loss as evidenced by a further 0.8 cm drop in MUAC since the last certification to 17 cm. Oral intake is limited to bites of pureed foods and sips of liquid. The patient requires a modified diet of pureed foods due to dysphagia. The patient has severely contracted upper and lower extremities with noted extremity muscle wasting, and facial muscle wasting with noted sunken orbits. PPS has been noted at 30%, however, due to limited oral intake, this is trending towards 20%. The patient's family continued to focus on comfort care.

This patient is an 89-year-old with a hospice diagnosis of Alzheimer's disease with dementia and dysphagia. Face to Face Encounter reviewed. The patient is non-verbal, lacking trunk and head control, bed bound, and at the very end stage of Alzheimer's disease with a FAST score of 7F. Over the course of the past benefit period, PPS has dropped from 30% to 20% as predicted at the last certification. The patient is eating pureed foods, due to dysphagia, in extremely small amounts, being carefully fed by his family, approximately 1-2 ounces per meal, sips of liquid. MUAC continues to trend downward, consistent with ongoing signs of weight loss, having dropped another 0.5 cm to 16 .5 cm. The patient has had worsening severely contracted upper and lower extremities with his heels contracted into his sacral area and arms are contracted into his chest, in the fetal position. Eyes are sunken, there is significant temporal and maxillary muscle wasting as well as extremity muscle wasting.

Discussion and Recommendations

The hospice plan of care must be reviewed, revised, and documented as frequently as the patient's condition requires, but no less frequently than every 15 calendar days.

Discussion and Recommendations

Person Centered Dementia Care

- centered on the whole person rather than the disease of the brain.
- centered on the abilities, emotions and cognitive capacities of the person.
- equally weighs the psychosocial context of the individual.

Discussion and Recommendations

Person Centered assessment:

- Recognizes the individuality of the patient.
- Recognizes that there are unmet needs that may be the basis of behavioral symptoms.
- Enables health care providers to understand and provide support for the unmet needs of the individual with dementia.
- Involves the individual and, where appropriate, their caregivers as much as they can contribute.
  - Incorporating personal knowledge of the person with dementia.
- Care and support should be tailored and delivered in line with the individual's preferences and wishes.
  - the individual's perspective is respected
  - the individual is treated with care, empathy, and dignity throughout the process.

Discussion and Recommendations

Address:

- Activities of Daily Living
- Caregiving Needs
- Advanced Care Planning
- Finances
- Emotional Support Needs
- Community Resource Needs
- Quality of Life
- Nutrition
- Home Safety
- Final Planning
- Symptom Management

Person Centered plan of care:

- Include all the disciplines:
- Home Health Aide
- Social Worker
- Chaplain
- Nurse
- Physician

Key Takeaways

- Use a whole person-centered, interdisciplinary approach in assessing the patient with dementia.
  - Utilize dementia specific resources such as the Alzheimer's Association.
- When describing the situation of a patient with end stage dementia, paint a detailed picture of the patient to demonstrate the changes that occur as they may not be as obvious as large changes in weight or functional status.
  - Capture increased caregiving requirements.

References

- Centers for Medicare and Medicaid Services (CMS) Local Coverage Determinations. Hospice – Determining Terminal Status https://www.cms.gov/medicare-coverage-database/view/lcd.aspx?lcdid=33393&ver=5&=
- National Institute on Aging https://www.nia.nih.gov
- Alzheimer's Association https://www.alz.org
- Kim SK, Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. Clin Interv Aging. 2017 Feb 17;12:381-397. doi: 10.2147/CIA.S117637. PMID: 28255234; PMCID: PMC5322939.
- Wisconsin Department of Health Services - Bureau of Aging and Disability Resources in collaboration with the Bureau of Quality Assurance Person-Directed Care Behavior Solutions Study Advisory Committee.

Session Evaluation and Certificate of Completion

- Your feedback is valuable as we plan upcoming sessions! Please complete the Project ECHO Dementia Care Miniseries Post-Session Evaluation

- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for participants who attend at least five live sessions and complete all session evaluations as well as a final miniseries evaluation

Upcoming Sessions

March 21

Providing Information, Education & Support to Patients and Families

March 28

Transitions in Care and Coordination of Services

April 4

Building and Supporting an Empowered Workforce

April 11

Reimbursement, Regulatory, and Quality

April 18

Summary and Wrap-Up

Additional Information

NHPCO Project ECHO webpage:

https://www.nhpco.org/regulatory-and-quality/quality/projectecho/

For more information:

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