Palliative and End-of-Life Care in PACE: Guidelines and Resources

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NATIONAL PACE ASSOCIATION
Advancing Programs of All-inclusive Care for the Elderly
www.NPAonline.org | (703) 535-1565
Traditional Care Model

Aggressive medical care

Hospice care

Time

Death
Transitions Care Model

- Curative
- Palliative Care
- EOL
- Bereavement
- Time
- Death
Final Years in PACE

Curative

Curative/Palliative

Palliative

NATIONAL PACE ASSOCIATION
A Good Death

<table>
<thead>
<tr>
<th>Ppt and family</th>
<th>Palliative/EOL Care</th>
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<tbody>
<tr>
<td>Control over the process</td>
<td>Participant and family at center of care at all times</td>
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<td>Environment of their choice</td>
<td>Open communication</td>
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<tr>
<td>Trust in caregivers</td>
<td>Management of pain</td>
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<tr>
<td>Treated with Dignity and Respect</td>
<td>Symptom control</td>
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<tr>
<td>Feeling supported</td>
<td>Address suffering</td>
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<tr>
<td>Address tasks of dying</td>
<td>Spiritual concerns</td>
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<td>Closure</td>
<td>Honor wishes</td>
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Since comprehensive care is provided to PACE participants, those participants who need end-of-life care will receive the appropriate medical, pharmaceutical, and psychosocial services through the PACE organization.
Workgroup History

• 2011 presentations at NPA Annual Conferences
• Collaborations with other PACE Organizations
• 2014
  • Initial discussion
• 2015
  • PCC and NPA support
  • PCC Survey Presentation
  • 1st official meeting at NPA annual conference
PACE Palliative and End-of-Life Care Survey
Demographic Information

- 30 PACE organizations

- Years of operation:
  - 0-5: 5
  - 5-10: 12
  - 15-25: 13

- Census:
  - 0-200: 11
  - 200-400: 10
  - 400-600: 5
  - 700-1114: 4
Survey Questions and Responses

• How you define palliative and end-of-life care?

• How do you determine participants in need of palliative and end-of-life care?
Survey Questions and Responses

• What kind of Palliative and End-of-Life training do you provide to all staff?

• Do you have a chaplain as part of your team?

• Do you have a system for assessing and addressing grief with participants, family, staff?
Please identify the top three EOL activities or resources in which your PO would be interested:

- Peer to peer learning on model EOL practices: 42.9%
- Development and distribution of model practice P&Ps on EOL care: 68.6%
- Advanced training for PACE staff: 57.1%
- Virtual EOL ethics and case committee to assist with challenging cases: 40.0%
- NPA organized training and certification on end of life care: 68.6%
I. Workgroup 2016
   • Purpose: To enhance Palliative and End-of-Life care in PACE organizations across the nation
   • Co-Chairs: Dory Funk and Tom Smith

II. Operational Resources T.F.
   • Chair: Dory Funk
   • Definitions & Guidelines

III. Training Resources T.F.
   • Chair: David Wensel
   • Training modules
# Workgroup and Task Force Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Organization/Program</th>
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<tbody>
<tr>
<td>Dory Funk</td>
<td>Medical Director</td>
<td>Senior CommUnity Care of Colorado</td>
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<tr>
<td>Maria DePasquale</td>
<td>Palliative Care RN</td>
<td>Community LIFE</td>
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<tr>
<td>Thomas Bracken</td>
<td>Senior Chaplain</td>
<td>Community LIFE</td>
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<tr>
<td>Suzanne Hartmann</td>
<td>Primary Care Physician</td>
<td>Community LIFE</td>
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<tr>
<td>David Wensel</td>
<td>Medical Director</td>
<td>Midland Care PACE</td>
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<td>Peter DeGolia</td>
<td>Medical Director</td>
<td>McGregor PACE</td>
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<tr>
<td>Craig Bethune</td>
<td>Physician</td>
<td>Care Resources</td>
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<tr>
<td>Eric Baum</td>
<td>Nurse Practitioner</td>
<td>McGregor PACE</td>
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<tr>
<td>Tom Smith</td>
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<tr>
<td>Igmara Prunier</td>
<td>Chaplain</td>
<td>Riverside PACE</td>
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<tr>
<td>Ellen Doyle</td>
<td>Nurse Practitioner</td>
<td>NewCourtland Senior Services</td>
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<tr>
<td>Amy Denham</td>
<td>Physician</td>
<td>Piedmont Health SeniorCare</td>
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<tr>
<td>Claudine Clarke</td>
<td>Medical Director</td>
<td>NewCourtland Senior Services</td>
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<td>Mary Obee</td>
<td>Learning &amp; Development Manager</td>
<td>Riverside PACE</td>
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<tr>
<td>Laural Alesi</td>
<td>Clinical Nurse Manager</td>
<td>Summit ElderCare</td>
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<td>Amol Ekhande</td>
<td>Medical Director</td>
<td>Genesys PACE of Genesee County</td>
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<tr>
<td>Sharon Reilly</td>
<td>Medical Director</td>
<td>Piedmont Health SeniorCare</td>
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<tr>
<td>Monica Updyke</td>
<td>CRNP</td>
<td>SeniorLIFE Johnstown</td>
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<tr>
<td>Lisa Mayo</td>
<td>Nurse</td>
<td>Riverside PACE</td>
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<td>Randy Ferrance</td>
<td>Physician</td>
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<tr>
<td>Elizabeth Grady</td>
<td>Physician</td>
<td>East Boston Elder Service Plan</td>
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<tr>
<td>Tara Horr</td>
<td>Advanced Practice Practitioner</td>
<td>McGregor PACE</td>
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<tr>
<td>Emily Krueger</td>
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<td>ElderONE</td>
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<tr>
<td>Shawn Bloom</td>
<td>President and CEO</td>
<td>National PACE Association</td>
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<tr>
<td>Rhonda Rose</td>
<td>SVP, Finance &amp; Administration</td>
<td>National PACE Association</td>
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<tr>
<td>Sarah Booth</td>
<td>Social Work Program Manager</td>
<td>Providence ElderPlace in Portland</td>
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<td>Adam Burrows</td>
<td>Medical Director</td>
<td>Upham's Elder Service Plan/PACE</td>
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<td>Susan Nelson</td>
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<td>Luz Ramos-Bonner</td>
<td>Network Medical Director</td>
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<td>Elizabeth Canino</td>
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<td>PACE Organization of Rhode Island</td>
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<tr>
<td>Le'Roi Gill</td>
<td>Chaplain</td>
<td>Mercy LIFE - West Philadelphia</td>
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[Image: National PACE Association Logo]
Operational Resources Task Force

• Definitions
• Guidelines
• Politics anyone?
Difficult Definitions

SCHRODINGER’S CAT WALKS INTO A BAR

...AND DOESN'T
Palliative Care

• Palliative care in PACE is participant and family-centered care coordinated by the IDT which is directed toward improving quality of life and relieving suffering.

• It addresses physical, psychological, social, and spiritual needs of the participant and family in the setting of serious illness.

• Palliative care may be provided concurrently with curative strategies.

• Focus is clarified through the alignment of goals of care.
End-of-Life Care

• End-of-life Care in PACE is participant and family-centered care coordinated by the IDT which is directed toward improving quality of life and relieving suffering in the last months, weeks, days of life when the goal of care is no longer curative.

• It addresses physical, psychological, social, and spiritual needs of the participant and family in the setting of advanced life-limiting illness.

• Focus is clarified through the alignment of goals of care.
To provide quality patient and family centered care for participants through the end of life via comprehensive interdisciplinary care with attention to the relief of suffering, effective communication, care for the dying and bereaved, and quality improvement. Intent is to perform this care in the home whenever possible.
Guidelines: Procedure

- Procedure:
  - EOL Committee
  - Participant Orientation
  - Criteria for Ppts to receive EOL care
  - Family care conference
  - Criteria for includes on transition care monitoring list
  - Monitoring status
  - Homebound Ppts
  - Institutional setting
  - At time of death
  - Bereavement Care
End of Life Committee

• Required (core membership):
  • Physician or Nurse Practitioner
  • Day Center Director
  • Registered Nurse
  • Social Worker
  • In-home Services Supervisor
Other members of the EOL Committee can include but is not limited to:

- Certified Nursing Assistants or Personal Care Assistants
- Dietician
- Physical Therapy
- Occupational Therapy
- Transportation
- Therapeutic Recreation
- Pharmacy Personnel
- Chaplain (highly recommended)
More on the EOL committee

- Frequency of EOL Committee meetings:
- Guideline Review
- Goals and functions
Goals and Functions

• promote quality end-of-life for the participants and participant’s families

• actively monitor the participants who are receiving EOL services.

• review and maintain the end-of-life educational materials that are given to families and participants

• coordinate, and promote continuing education and provide clinical support specific to end-of-life care for staff.
New Participant Orientation

• During intake process
• At initial assessment
• At post-enrollment care conference if applicable
• Ongoing as appropriate
Criteria for participants to receive end-of-life care
Criteria for participants to receive end-of-life care

• Any member of the PACE interdisciplinary team may alert
• Life limiting diagnosis
• Likelihood of death within “about six months”
• Participant and family agreement to primarily palliative medical treatment for current medical problems.
Initial implementation of end-of-life care: family care conference
Initial implementation of end-of-life care: family care conference
Initial implementation of end-of-life care: family care conference

• Presentation to the participant and family that the participant is approaching end-of-life.
• Participant and family wishes and needs.
• Advance care planning and code status documentation,
• Purpose and goals of EOL care
• Functions of the EOL committee.
• The plan to be enacted at the participant’s death
• Transitional care criteria, monitoring (RADAR LOVE)
• Organizational Monitoring of EOL participant status
• Homebound Participants
• End-of-life services in an institutional setting
• At time of death and/or immediately after death
And the rest of the document

• Bereavement care
Training Resources Task Force

• 10 Training Modules
• 15-20 slides each
• Each module has 3 learning objectives
• Talking points in the notes section
• Created to be presented in approximately 30 mins
1. Introduction to Palliative and End-of-Life Care in PACE

• **Author:** Tom Smith, LCSW

• **Learning objectives:**
  • Understand the Philosophy of Palliative and end-of-Life care in PACE
  • Define Palliative and End-of-Life Care in PACE
  • Introduce Key topics in providing high quality palliative and end-of-life care in PACE.
2. Advanced Care Planning: Conversations Do Change Lives!

• **Author:** Susan E. Nelson, MD, FACP, FAAHPM

• **Learning objectives:**
  - Discuss importance of advance care planning
  - Review advance care planning documents
    - Advance Directives/Present Directives
  - Health Care Power of Attorney
  - Discuss Physician Order for Life Sustaining Treatment (POLST)
3. Trajectories and Symptoms

• **Author:** David Wensel DO, FAAHPM

• **Learning objectives:**
  • Definition of End-of-Life
  • Difference between hospice and palliative care
  • Define common symptoms at End-of-Life
4. Self-Exploration
“Let’s get personal”

- **Author:** Ellen D. Doyle, CRNP,CS

- **Learning objectives:**
  - Have greater comfort in exploring personal End of Life decisions
  - Begin to formulate a document for communicating personal End of Life wishes
  - Have an increased comfort in discussing End of Life wishes with loved ones.
5. Communication and Difficult Conversations: We can do this!

• **Author:** Maria DePasquale RN, CHPN

• **Learning objectives:**
  
  • Describe communication processes and challenges in the setting of serious illness
  
  • Define important elements to ongoing communication and factors that influence communication with participants and families
  
  • Identify techniques for communicating bad news and discussing goals of care with participants and families
6. Family Dynamics
The Good, The Bad, & the Ugly

• **Author:** Maria DePasquale RN, CHPN

• **Learning objectives:**
  • Identify 3 patterns of relating within families
  • Define 3 important elements that influence how a family functions together
  • Describe 2 strategies for communication within family conflict
7. Cultural Considerations

• **Author:** Rev. Dr. Le’Roi Gil, J.D.

• **Learning objectives:**
  • To raise awareness of and enhance the care for people at end of life
  • To honor and appreciate cultural diversity
  • To understand how cultural factors influence end of life decision making
8. Loss, Grief, and Bereavement

- **Author:** Tom Smith, LCSW

- **Learning objectives:**
  - Define Loss, Grief, and Bereavement
  - Understand the basic types of grief
    - Anticipatory
    - Normal
    - Complicated
  - Discuss supportive techniques and resources
9. Ethical Issues

• **Author:** Rev. Thomas F. Bracken Jr. D Min

• **Learning objectives:**
  • Address ethical questions that arise when treating the dying patient
  • To understand the impact of healthcare decisions
  • This overview will provide a starting place for those wishing to explore the complex subject of death and dying
10. Final Hours

• **Author:** Lisa G. Mayo, RN

• **Learning objectives:**
  - Sign and symptoms of imminent death
  - Assessment of needs and interventions for the dying patient and family
  - Care following death
How to access resources

• NPA members
• NPA Website
  • Member Resources
  • Participant Care Resources

• [http://www.npaonline.org/member-resources/participant-care-resources](http://www.npaonline.org/member-resources/participant-care-resources)
Introduction to Case Studies

• Election of Hospice Benefit

• Collaboration with Hospice Agency

• In-house Palliative & EOL program
Panel Discussion/Questions