

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



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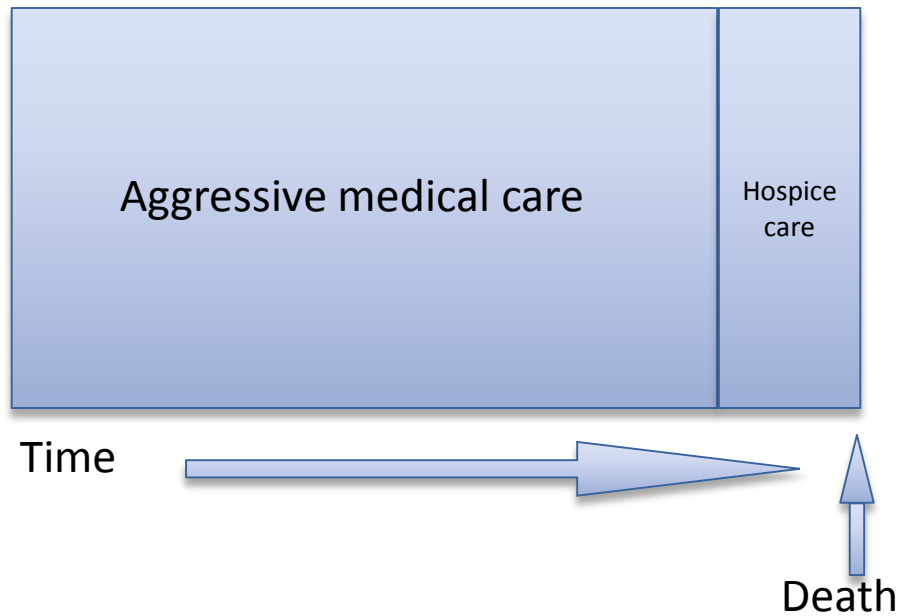
NATIONAL PACE ASSOCIATION

Advancing Programs of All-inclusive Care for the Elderly

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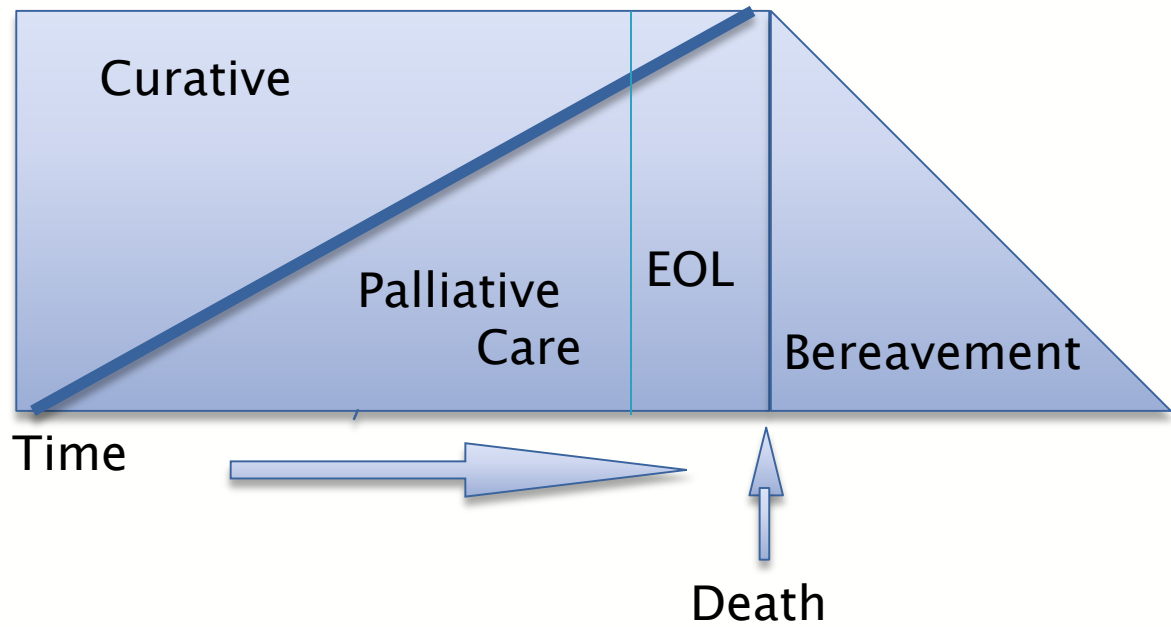


Traditional Care Model

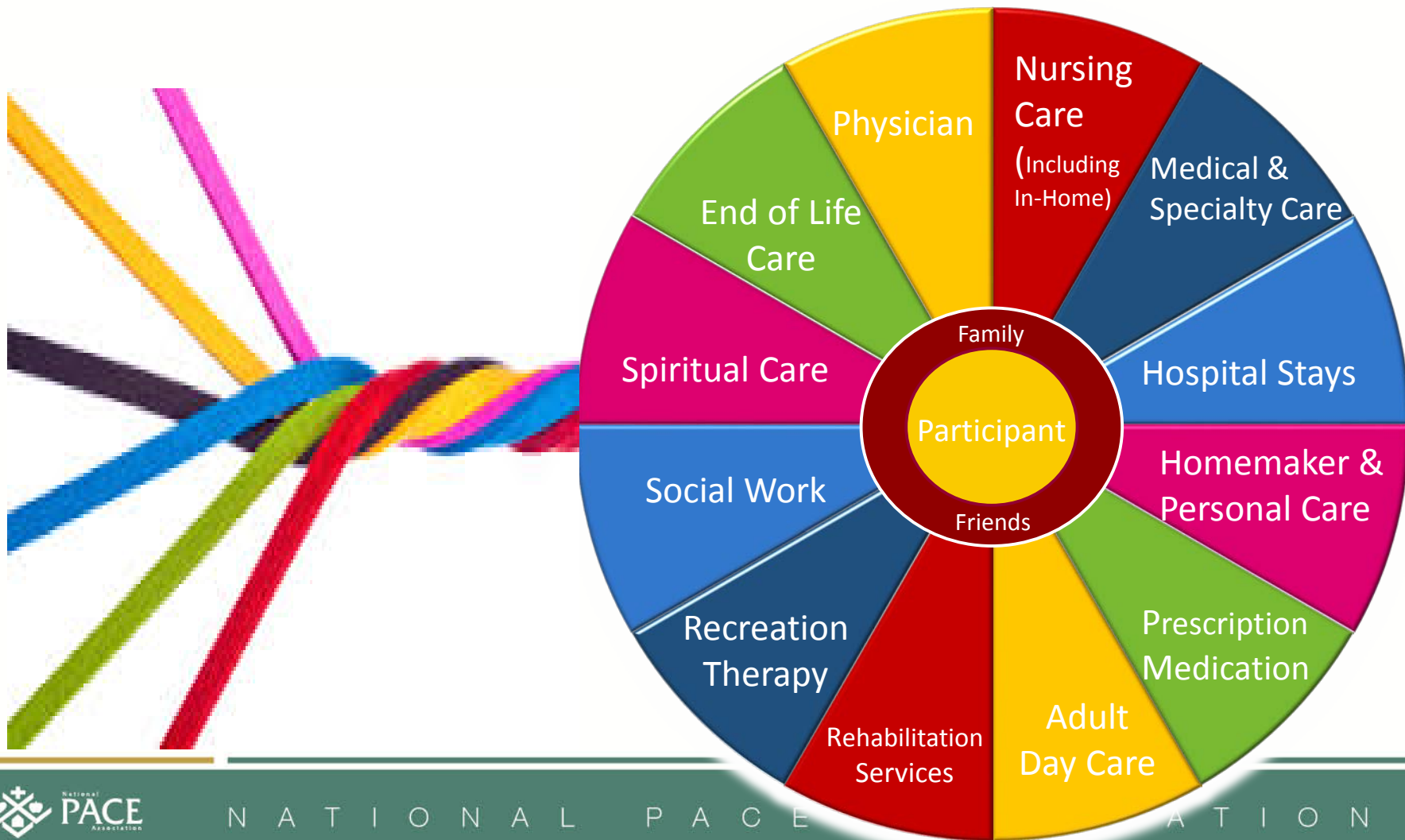




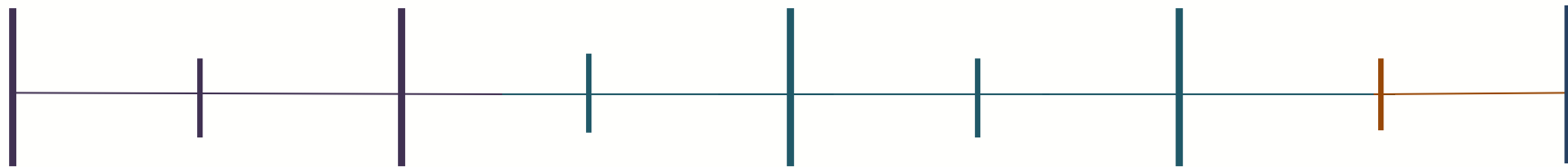
Transitions Care Model



PACE



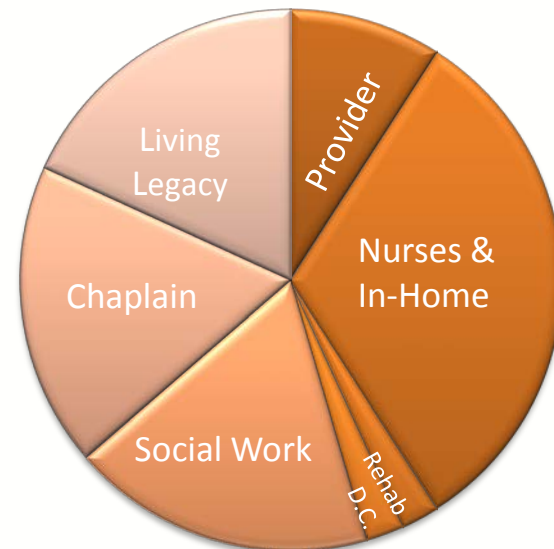
Final Years in PACE



Curative

Curative/Palliative

Palliative



A Good Death



| Ppt and family | Palliative/EOL Care |
|----------------------------------|---|
| Control over the process | Participant and family at center of care at all times |
| Environment of their choice | Open communication |
| Trust in caregivers | Management of pain |
| Treated with Dignity and Respect | Symptom control |
| Feeling supported | Address suffering |
| Address tasks of dying | Spiritual concerns |
| Closure | Honor wishes |



CMS PACE Regulations: EOL Care

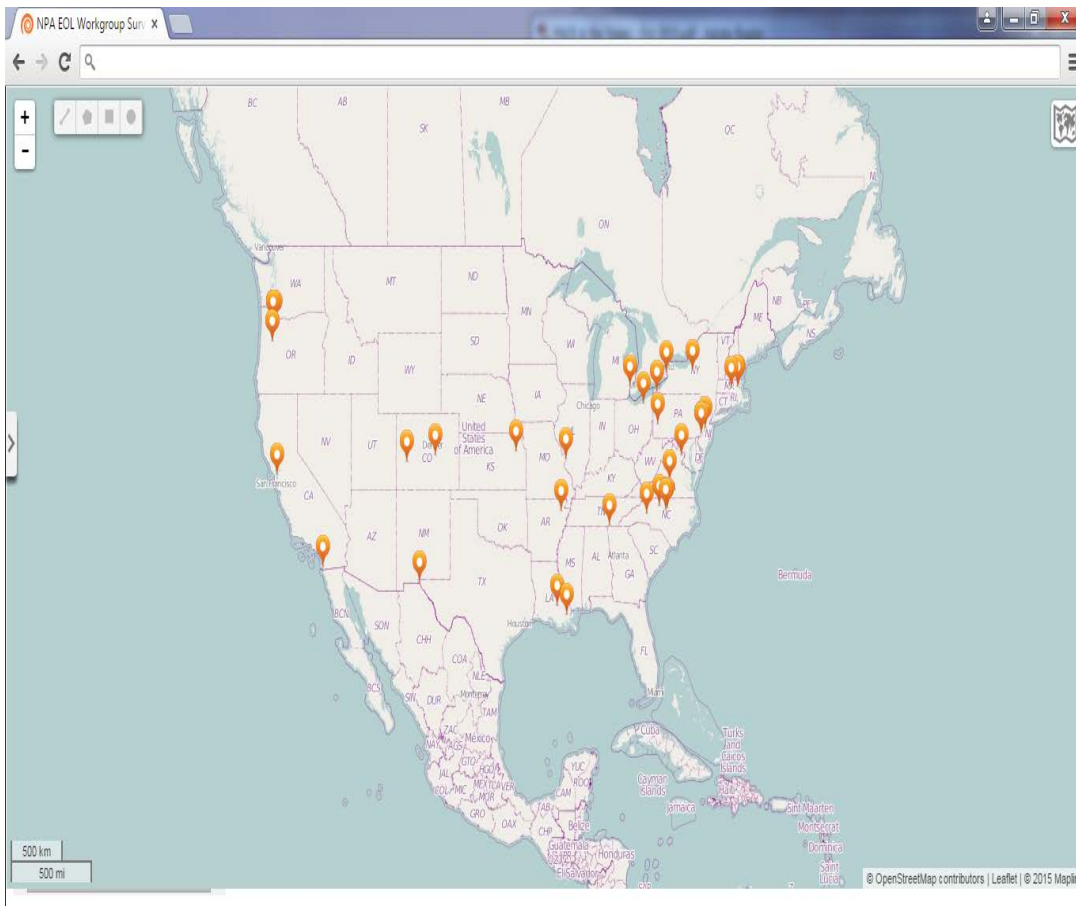
- Since comprehensive care is provided to PACE participants, those participants who need end-of-life care will receive the appropriate medical, pharmaceutical, and psychosocial services through the PACE organization.



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**

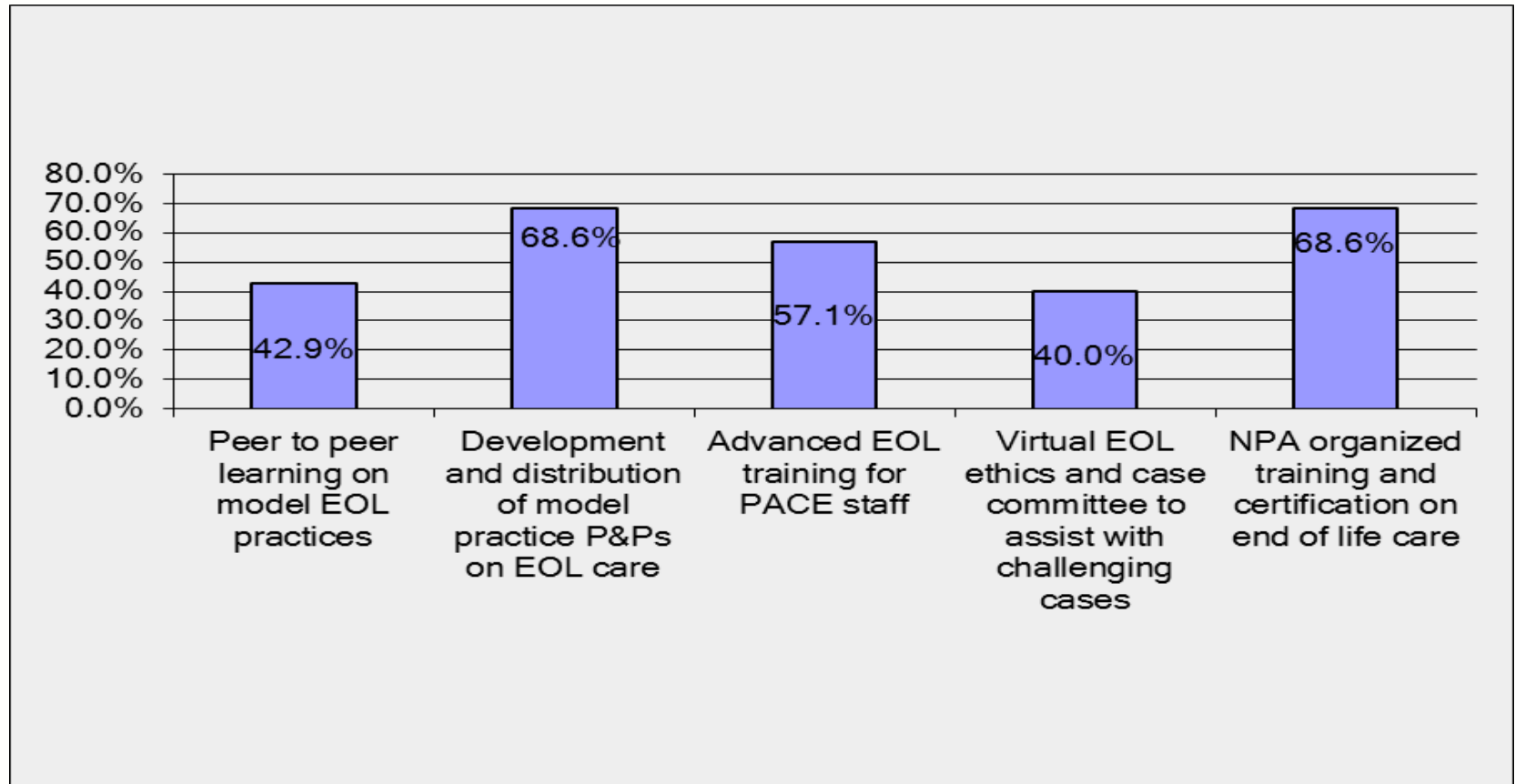
Survey Questions and Responses

- 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:



Palliative and End-of-Life Care Workgroup



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



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

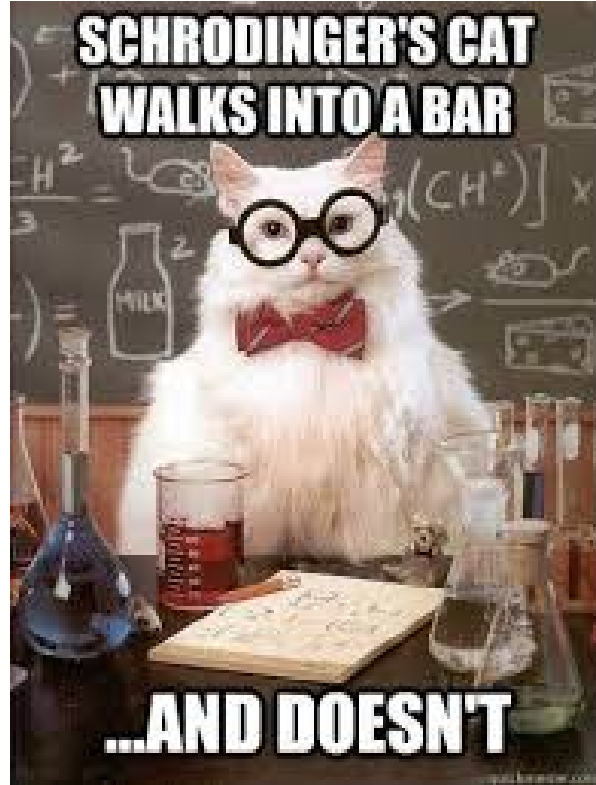
Operational Resources Task Force

- Definitions
- Guidelines
- Politics anyone?





Difficult Definitions



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.

EOL Care Operational Guideline

- 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

And the rest of the document



- 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)

LOUISIANA PHYSICIAN ORDERS FOR SCOPE OF TREATMENT (LaPOST)

FIRST follow these orders. THEN contact physician. This is a Physician Order form based on the patient's medical condition and preferences. Any section and completed section full treatment for that section. LaPOST complements an Advance Directive and is not intended to replace that document. Everyone should be treated with dignity and respect. Please see www.LaPOST.org for information regarding what my cultural/religious heritage tells me about end of life care.

PATIENT'S DIAGNOSIS OF LIFE LIMITING DISEASE AND IRREVERSIBLE CONDITION: _____

GOALS OF CARE: _____

A. CARDIOPULMONARY RESUSCITATION (CPR): DESIRED UNDESIRABLE (PLEASE INDICATE NOT DESIRED)

CPR/Intervent Resuscitation (requires full treatment in section B) Do not resuscitate (do not attempt to restart heart or breathing)

B. MEDICAL INTERVENTIONS: PERSONAL (PLEASE CHECK ALL APPLYING)

FULL TREATMENT (primary goal of providing the best medical outcome based on treatment in Section Treatment and Comfort Focused treatment, and maximal analgesia, sedation and/or palliation and hospice care)

SELECTIVE TREATMENT (primary goal of providing the best medical outcome based on treatment in Section Treatment and Comfort Focused treatment, and maximal analgesia, sedation and/or palliation and hospice care while avoiding burdensome treatments like treatment in Comfort Focused treatment, but maximal analgesia, sedation and/or palliation and hospice care)

COMFORT FOCUSED TREATMENT (primary goal is maximizing comfort (as indicated by any note to provide pain and symptom management, analgesia, sedation and/or palliation and hospice care) in response to patient's wishes and/or family requests. Do not use treatments listed in full or selective treatment unless consistent with goals of care. Do not use treatments listed in comfort focused treatment unless specifically provided in comfort setting)

C. ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION: (always after food/fluids by mouth as tolerated)

Full amount (as tolerated)

Full period of artificial nutrition by tube (G-tube)

Long term artificial nutrition by tube (if needed)

D. SUMMARY

Discussed with: Patient (Patient has capacity) Personal Health Care Representative (PHCR)

The items for these orders are: Patient's Declaration (can be oral or nonverbal) Advance Directive (added, available and reviewed)

Patient's Personal Health Care Representative Advance Directive (if present)

Qualified Patient (with capacity) No Advance Directive

Patient's Advance Directive, if indicated, patient has completed an additional document that provides guidance for treatment Health care agent if named in Advance Directive

Physician's Practice Name: _____ Name: _____
Address: _____ Phone: _____

Physician Signature: _____ Date: _____

PHCR Relationship: _____ PHCR Signature: _____ PHCR Phone Number: _____

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED
USE OF ORIGINAL FORM IS STRONGLY ENCOURAGED. PHOTOCOPIES AND FAXES OF SIGNED LAPOST FORM ARE LEGAL AND VALID.

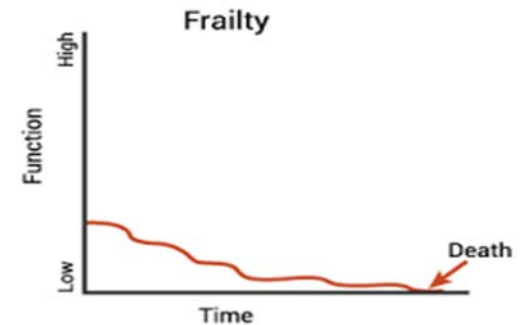
3. Trajectories and Symptoms



- **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”

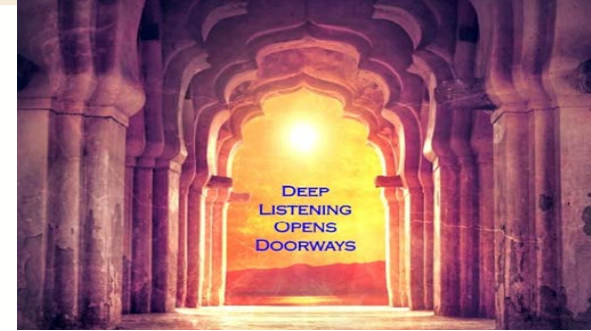
- **Author:** Ellen D. Doyle, CRNP,CS
- **Learning objectives:**
 - Have greater comfort in exploring personal End of Life decisions
 - Begin to formulate a document for communicating personal End of Life wishes
 - Have an increased comfort in discussing End of Life wishes with loved ones.



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





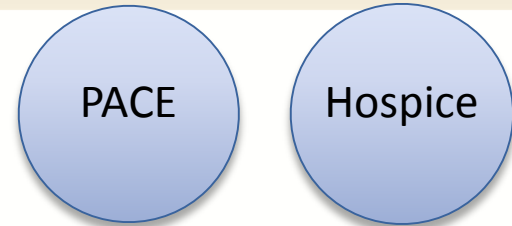
How to access resources

- NPA members
- NPA Website
 - Member Resources
 - Participant Care Resources
- <http://www.npaonline.org/member-resources/participant-care-resources>

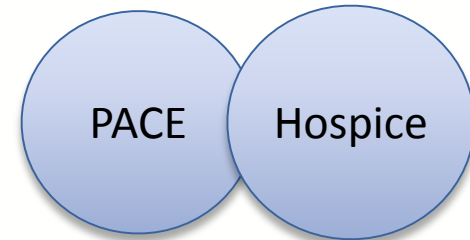
Introduction to Case Studies



- Election of Hospice Benefit



- Collaboration with Hospice Agency



- In-house Palliative & EOL program





Panel Discussion/Questions